



Resilience of Saudi Families with Chronically Ill Children

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD)

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Abstract

Parents have an expectation that their children will grow and develop in a healthy manner physically, emotionally and socially. Hence when a child is diagnosed with a chronic condition, parents' expectations are challenged. This research study explores resilience among Saudi families, when faced with the burden of a child's chronic illness, in three main public hospitals in the Jeddah region of Saudi Arabia. It seeks to identify the factors that influence resilience among Saudi families.

This study emphasises the need for further exploratory research regarding this topic in Saudi Arabia. This is especially important due to the fact that Saudi Arabia (and most nations in the Middle East region), for the increase of chronic illness in children. This highlights the preferences for the concept of communal existence and the emergence of patriarchal leaders. It is also worth noting that religion may also be a key differentiating factor in exploring the factors that lead to family resilience.

This descriptive, exploratory cross-sectional study examined and described the factors that influence the development of resilience in Saudi families with chronically ill children. Quantitative and qualitative data were collected in three public hospitals in the Jeddah region of Saudi Arabia. The aim was to determine the approaches employed by these families to become resilient and to identify the factors that led them to emerge even stronger in the face of adversity. Data were collected in two concurrent phases. In the first phase, 122 Saudi parents were surveyed to identify which factors they believed led to resilience. The second phase consisted of face-to-face interviews with 15 registered paediatric nurses to obtain information on their objective observations of

how they felt Saudi parents were coping with having a chronically ill child. Furthermore, 12 face-to-face interviews with Saudi mothers were undertaken to explore and identify an in-depth understanding of what the concept of resilience means to them. Quantitative data were analysed through the Statistical Package for the Social Sciences (SPSS, V20.0); descriptive and inferential statistical tests were utilised. Qualitative data were analysed with a thematic approach, using NVivo 10® qualitative analysis software.

The findings from the inferential analyses supported the model suggesting that individuals with High Stress and Adversity combined with High sense of quality of life (QOL) demonstrated resilience, which is affected by demographic variables as well as social support and general self-efficacy. The results of the study demonstrated significant relationships between self-efficacy and social support on resilience.

The content analyses of the interviews revealed the factors perceived to reduce family stress and increase the ability to cope include parents' reliance on God and prayer, and parents' educational levels and effective staff communication with the parents.

The findings of the study emphasise the importance of a thorough and holistic assessment of families, their social environments and the level of support they require to assist them to cope and become resilient.

Keywords: chronic illness, family resilience, resilience, stress, quality of life, coping, support

Declaration

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis/project is the result of work which has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and, ethics procedures and guidelines have been followed.

Mrs. Nouran Essam S Katooa

11th December 2014

Dedication

I firstly honour and am grateful to the inspiration of Allah, for enabling me to complete this work. I gratefully dedicate all my achievements:

- To King Abdullah Bin Abdulaziz for his constant support.
- To my great father, Essam Katooa, and my lovely mother, Eman Baharith, who both wished me to have the best of everything, and I thank them for their unconditional love, support, unlimited care and prayers throughout my life and indeed during all my research studies.
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List of Abbreviations

ANOVA	Analysis of Variance
BSN	Bachelor of Science in Nursing
CDSI	Central Department of Statistics and Information
CHEAN	College Human Ethics Advisory Network
CHiRP	Child Illness and Resilience Program
DAS	Dyadic Adjustment Scale
EFT	Emotionally Focused couple Therapy
FAAR	Family Adjustment and Adaptation Response
FCOPES	Family Crisis Oriented Personal Evaluation Scale
FES	Family Environment Scale
FHI	Family Hardiness Index
FSC	Family Sense of Coherence Scale
Gov	Government
GSE	General Self-efficacy
HCP	Health Care Professionals
ISG	Information Support Group
JRA	Juvenile Rheumatoid Arthritis
KIPP	Kansas Inventory of Parental Perceptions
KSA	Kingdom of Saudi Arabia
MOE	Ministry of Education
MOH	Ministry of Health
MOHE	Ministry of Higher Education
MSIS	Miller Social Intimacy Scale
MSN	Master of Science in Nursing
NHMRC	National Health and Medical Research Council
POS	Parent Outpatient Survey
PSI	Parent Stress Index
QOL	Quality of Life
RFS	Relatives and Friend Support Index
RMIT	Royal Melbourne Institute of Technology
SB	Spina Bifida
SCL-90-R	Symptoms Checklist 90-Revised
SED	Severe Emotional Disturbances
SPSS	Statistical Package for the Social Sciences
SSI	Social Support Index
SSQ	Social Support Questionnaire
USA	United State of America
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
WLS	Wisconsin Longitudinal Study

Chapter One: Introduction and Overview

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Chapter 1 : Introduction and Overview

1.1 Introduction

Children are their parents' pride and joy. Parents have an expectation that their children will grow and develop in a holistic, healthy manner physically, emotionally and socially. When the life and health of a child is threatened by accident or illness, parents find themselves in an extremely vulnerable situation. Hence, when a child is diagnosed with a chronic condition, the parents' expectations are challenged and they grieve for the loss of their child's health (Lowes, Lyne & Gregory, 2004; Marshall, Fleming, Gillibrand & Carter, 2002).

Taking care of a chronically ill child is arguably one of the most draining and difficult tasks a parent can face. A child's chronic illness increases the risk of developing a range of difficulties, including physical, emotional, cognitive and psychosocial dysfunctions within the family (Lowes et al., 2004; Tsamparli & Kounenou, 2004). Children with a chronic illness change the family's established patterns of functioning. This disrupts the normal routines of everyday life. In turn, this leads to changes in relationships among family members (Anderson, Loughlin, Goldberg & Laffel, 2001; Barlow & Ellard, 2006; Charron-Prochownik, 2002; McCubbin & McCubbin, 2001; Patterson, 2002). These changes can add to the range of challenges a family has to cope with due to the child's illness, and can lead to increased stress levels within the family. The family's ability to cope with this stress is important, as stress has been found to have a negative impact on health (Amato, 2005; Mackay, 2005). Some parents are more likely to succumb to disorders such as anxiety and depression. However, some parents do not experience adverse outcomes and deal with

the health issue instinctively, getting on with their lives in a positive and productive way. Psychologists have labelled those with the capacity to cope with stress, maintain their equilibrium and adapt to adversity as being resilient. This study focuses on how resilience is displayed by Saudi family members when faced with the burden of a child's chronic illness. The aim of this chapter is to provide an overview of the study's rationale, aims and objectives, research questions and conceptual framework, as well as outline the thesis organisation. There are studies that emphasises the positive aspects of having a chronically ill children, the focus of this study, however were on resilience and there negative side.

1.2 Background of the Study

In the past two decades, there has been an alarming increase in the prevalence of chronic diseases among children in Saudi Arabia, such as diabetes, hypertension and heart disease, cancer, genetic blood disorders and childhood obesity (Al-Qurashi, El-Mouzan, Al-Herbish, Al-Salloum & Al-Omar, 2008; Al-Turki, 2000; World Health Organization (WHO), 2010). Disease patterns in the Kingdom of Saudi Arabia (KSA) have changed over time from communicable to non-communicable and chronic diseases affected by lifestyle changes. The Ministry of Health (MOH) *Statistics Year Book* (2011) reported the most common chronic illnesses among children aged 14 years and below in Saudi Arabia between 2009 and 2011 (see Table 1.1).

Table 1.1

General Chronic Illnesses Among Children (Aged >14 years) in Saudi Arabia in 2009 & 2011

	Diabetes Mellitus	Respiratory Diseases	Blood & Immunity Diseases	Neurological & Psychological Diseases	Eye Diseases	ENT Diseases	Hypertension	Cardiovascular Diseases	Urinary System Diseases	Diseases of Digestive System
Saudi Arabia										
2009	44998	182291	62004	66988	213359	158707	16089	7311	79931	258689
2011	37576	164225	52177	57990	194639	152391	11169	4931	73352	406081
Jeddah										
2009	11900	87211	5282	2493	1139	5740	90	131	3900	3599
2011	12759	82741	3668	3160	1142	5358	96	146	3800	5137
Jeddah %										
2009	26.45%	47.8%	8.52%	3.72%	0.53%	3.62%	0.56%	1.79%	4.88%	1.39%
2011	34%	50.4%	7.03%	5.45%	0.58%	3.52%	0.86%	2.96%	5.2%	1.27%

In 2009 and 2011, the Saudi MOH conducted two consecutive studies to identify chronic illnesses among children in the Jeddah region. This study showed that the five most common diseases in children with long term effects were respiratory diseases (such as pulmonary infections and bronchial asthma), leukaemia, diabetes mellitus, anaemia and brain tumours (see Table 1.2).

Table 1.2

Most Common Chronic Illnesses Among Children Aged 5–14 years in Jeddah, Saudi Arabia in 2009 & 2011

Chronic Illness	Jeddah	
	2009	2011
Respiratory Diseases	48%	50%
Leukaemia	40%	38%
Diabetes Mellitus	27%	34%
Anaemia	21%	28%
Brain Tumour	13%	20%
Tuberculosis	Incident rate 807/100,000 cases 49 children	Incident rate 792/100,000 cases 28 children

The Saudi Council of Health Services (MOH, 2009) stated that approximately ten per cent of Saudi families in the Jeddah region have a child with a chronic illness, and 121,000 children aged 5–14 years in the same region are diagnosed with a chronic illness. In some instances, the chronic illness may last for the child's lifetime: for example, cystic fibrosis, diabetes, asthma, epilepsy, cancer and autism.

From the onset of a child's diagnosis of chronic illness, families—particularly the parents who have primary responsibility for taking care of their child—undergo a series of emotional, social and psychological challenges. According to Sachdeva (2008), there are two identifiable approaches taken by most family members of chronically ill children. The first approach is pessimism towards the situation. This is characterised by resignation, self-denial, helplessness and a lack of hope. The second approach is characterised by the assumption that the situation does not exist, a state of complete

denial. Both approaches, according to psychologists, are geared towards creating a sense of momentary relief and escape from reality. These approaches might function adequately in the short term for parents, but might affect other family members negatively (Glicken, 2006). Understanding how people respond to a situation is important in structuring clinical interventions and support services that can be made available (Longaretti, 2008).

It is therefore important to understand the issues surrounding families of children with chronic illnesses, and in particular the negative and positive effects of such illnesses on parents and siblings (Al-Turki, 2000; Rao & Beidel, 2009; Reichman, Corman & Noonan, 2008). It is also extremely important to assess the family environment associated with the presence of an ill child, and its effects on relationships among family members. This study focused on Saudi family that may help who have children with chronic illnesses in order to identify strategies to support these families.

1.3 The Phenomenon of Resilience

Human beings adopt various approaches when dealing with physical and psychological stressors. Chronic illness in a child not only affects that child's lifestyle, but also the child's family members, who are affected physically, emotionally, psychosocially and economically.

Other families of chronically ill children are prone to developing dysfunctional psychosocial behaviours that affect family harmony and the activities performed by family members; these are non-coping families (Barlow & Ellard, 2006; Dickman & Gordon, 1985; Havens, 2005). Some family members of chronically ill children find themselves coping positively with the situation and employing various approaches, in an

attempt to adapt to the situation (Amato, 2005; Hasting, 2003; Knafl & Zoeller, 2000; Mackay, 2005). Such families appear to use their strengths and ‘bounce back’ from adversity (Patterson, 2002). This ability of a family to bounce back is referred to as resilience (Compton, 2005; Walsh, 2006).

Resilience is an important attribute because it provides family members with the capacity to resist adopting destructive behaviours, such as social withdrawal, stress, depression, indifference and other negative behaviours that might emerge during such challenging situations (Barlow & Ellard, 2006; Walsh, 2006). Resilience was defined by Walsh (2003) as ‘the ability to withstand and rebound from adversity’ (p. 130). Resilience is often discussed in terms of risk and protective factors that help shape the individual’s ability to endure in the face of adversity (Luthar, 2006; Masten & Reed, 2002; Rutter, 1985). It is a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti & Becker, 2000). Consequently, the phenomenon of resilience has emerged as a source of positive adjustment and adaptation in current Western literature.

Initially, resilience theory focused primarily on the individual (Walsh, 2006). It was seen as an innate characteristic of individuals, and families were viewed as contributing to risk, but not to resilience. However, the concept of resilience has been extended to the family system. This paradigm shift has led to the development of the term ‘family resilience’, which is defined as ‘characteristics, dimensions, and properties of families that help them to be resistant to disruption in the face of change, and be adaptive in the face of crisis situations’ (McCubbin & McCubbin, 2001, p. 247). This approach fundamentally altered the perception of viewing troubled families as damaged

and beyond repair, to seeing them as challenged by life's adversities with the potential for fostering healing and growth in all members (Patterson, 2002; Walsh, 2003). This perspective enables one to focus on factors that aid survival and success, instead of focusing on what contributes to failure.

A thorough search of the literature emphasises the paucity of resilience literature in Saudi Arabia. A better understanding of Saudi families' feelings when confronted with a crisis would clarify how nurses and the Saudi health care system can assist families to maintain balance and healthy functioning in the face of adversity. More explanation of the resilience phenomenon and a detailed critical literature review will be discussed in Chapter 3.

1.4 Rationale of the Research

Prior to the discovery of oil, the Saudi Arabian economy was limited, relying on trading, fishing, farming and religious tourists travelling to the two holy cities of Makkah and Madina. In 1970s, the Kingdom of Saudi Arabia (KSA) was among the least-developed economies. Now, Saudi Arabia's oil grants it a high profile among the world's trading countries and plays a major role in the country's advanced economy and industry. Since the discovery of oil, KSA has witnessed a dramatic increase and improvement in socioeconomic developments, with notable progress in the development and planning of infrastructure, technology, education, health, housing and the environment (Sullivan, 2012).

Consequently, the broader society has changed. Family cohesion was stronger in the past, and families were more supportive with stronger social relationships. There was little concern about education or long term aspirations. Traditionally in Saudi

families, the father was the ‘breadwinner’ and the mother was the ‘home keeper’. Women were not expected to work outside the house, and their primary role in society was to raise children and take care of the household (Sullivan, 2012). They stayed at home and performed the essential role of homemakers and caregivers (Brown, 2005). The extended family lived together and the members were more supportive of each other; their social relationships and bonds were stronger.

The rapid economic change since the chronically ill child has influenced family structures in Saudi Arabia. Since 1970, almost all young females have gone to school. Saudi women are now playing a vital role in the wider Saudi community. Their employment opportunities have increased dramatically over the last few years, and mixed gender workplaces have developed, particularly in banking, finance and health care. Social relationships in Saudi society are changing due to the effects of urbanisation, industrialisation and education, and the Saudi family has become nuclear (Sullivan, 2012).

Rapid advancements in technology have led to positive effects on the health care system. Healthcare services in KSA have undergone remarkable development and significant progress over the last few decades. However, advanced development in technology has also changed the family structure, people’s lifestyle and has negatively affected children’s development. The impact of rapid advances in technology on a developing child has seen an increase in physical, psychological and behavioural disorders that the health and education systems are just beginning to detect. Technology overuse is one of the factors that have been contributed to childhood obesity and diabetes (Al-Mazmi, Aslam & Rajan, 2013).

Considering the high rate of chronic illnesses among Saudi children diagnosed every year (Al-Qurashi et al., 2008) it is imperative to examine various ways in which Saudi parents cope with and adapt to life changes when they have a child diagnosed with a chronic long-standing illness. Examining the social environment and level of support received from family, friends and healthcare providers is essential for health professionals to understand how to support and enhance the Saudi parents' capacity to maintain their own relationships and relationships with others. It is crucial to identify and reduce the potential negative effects of childhood illness on Saudi families, and to explore strategies that may assist the families to deal with the situation. Some families are unaware of the support services available to them and end up dealing with the stressors by themselves, with no life experience to draw upon (Longaretti, 2008).

Having an infant or a child diagnosed with a chronic illness can be a devastating event for families. Parents of a chronically ill child may struggle to meet the demands of parenting. They are required constantly to change their lifestyle and roles as a parent. The nature of the disease, the need to manage the symptoms and the complexity of the treatment all cause emotional strain. This begins with a period of uncertainty surrounding the child's health condition (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2004). Parents of chronically ill children often become emotionally strained as a result of not knowing what they should do for their child, and not being able to participate in taking care of their hospitalised child (Hopia et al., 2004). When a child is diagnosed with a chronic illness, the family as a unit experiences a range of emotions such as shock, sadness, fear, nervousness, frustration, anger and sorrow (Sallfors & Hallberg, 2003).

A child's chronic illness has extreme effects on family functioning and the relationships among the family members. Parents may experience guilt resulting from difficulties in caring for their ill child (Hamlett, Pellegrini & Katz, 1992). Parents of a chronically ill child might have difficulties being together as a couple, and their parental experiences and coping styles may also change (Graungaard & Skov, 2007; Hopia et al., 2004). The hopes and expectations they had for their child may be shattered, and they may feel unable to protect their family.

Parents may experience worry and fear for their child, for themselves and for other family members. They may worry about the pain their sick child will experience from medical procedures, the influence of the illness on their child's development, and the impact on the broader family unit. Parents may worry about their caregiving role, which may extend indefinitely into the future, and they may doubt their ability to manage the demands that will be placed upon them. They may feel stressed, angry, depressed, anxious, and guilty and they may become more protective. Parents may also have to reconsider their working lives, as one parent may need to give up work, and medical costs are likely to add considerably to a family's expenses. The ongoing stress and expenses of health care for a child with a chronic illness can be physically and emotionally overwhelming. Negotiating with service providers can also be confusing and exhausting (Taanila, Syrjälä, Kokkonen & Järvelin, 2002).

Throughout caring for a sick child, parents may feel lonely and isolated. They may become socially isolated and lose friends because of the demands of caring for an ill child. Participating in social activities is difficult when parents have to manage wheelchairs, medical supplies, special diets and difficult behaviour. It is often simpler

just to stay at home (Graungaard & Skov, 2007). When there are other children in the family, parents need to devote considerable time and energy to other children. It is difficult for parents to cope with such a situation; coping is even harder for children, who lack maturity and understanding.

Young children may not be capable of understanding their sibling's illness, and might think they have caused it or might catch it, resulting in feelings of guilt and responsibility. The healthy siblings may feel that nobody is taking care of them; in other words, they feel they will never be the centre of attention in their family. The parents' attention is often concentrated on the ill child, and that might make them feel jealous of the constant attention towards the ill child (Hopia et al., 2004). As consequence, the well siblings may become anxious, and feel unfairly treated. Time alone with one parent is precious, but time with both parents can be rare. Healthy siblings may be angry that their parents cannot attend events together, the way other parents can. They want to be treated equally. Healthy siblings may also feel jealous of the ill child, who may be allowed to behave in ways that are not acceptable in the well sibling. This can be a source of resentment for the entire family (Strohm, 2002; Taanila et al., 2002).

Moreover, healthy siblings may be expected to mature more quickly than the ill child and help their family with household duties, care for the ill child, or at least look after themselves (Strohm, 2002). Healthy siblings may miss out on the features of a traditional sibling relationship when their brother or sister has a chronic illness, such as spending time together, sharing toys, rooms, friends, playing, arguing and fighting, and experiencing joy and laughter. These siblings cannot experience companionship and support for each other, and learn social skills such as negotiation and co-operation

(Strohm, 2002; Taanila et al., 2002). This is an important issue that should be mentioned and described but its not part of this study.

This study seeks to describe and explore approaches adopted by Saudi families when faced with a chronically ill child and to explore Saudi families' expectations of the support offered by the Saudi healthcare system. It is important for families to adopt a resilient approach when faced with the adversity of having a chronically ill child. This will ensure that the family as a basic unit is able to withstand the range of challenges it faces when dealing with such a situation. Saudi society includes families, and when the family is dysfunctional, the broader society may be at risk of becoming dysfunctional.

1.5 Study Aims and Objectives

This study aims to describe and explore the concept of resilience in Saudi families who have chronically ill children. The specific objectives of this study are as follows:

1. To explore and identify factors that contributing resilience of Saudi parents when faced with the adversities of chronically ill children.
2. To explore the relationships between family resilience and a chronic illness of a sick child.
3. To investigate the type of support Saudi families receive from the healthcare system, visiting healthcare professionals, religious leaders, social and family networks.
4. To explore nurses' perspectives on the support offered by the Saudi healthcare system to these families.

1.6 Research Questions

From the aims described above, the following major questions relevant to the current study context have emerged:

1. What are the factors associated with resilience among Saudi families with chronically ill children?
2. What are the relationships between family resilience and the chronic illness of a sick child?
3. What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities associated with chronically ill children?
4. How does the Saudi healthcare system assist in strengthening Saudi families when adjusting to the adversity associated with chronic health conditions?
5. What factors contribute to resilience in Saudi families?

1.7 Conceptual Framework

Current research directions are emphasising the socio-ecological concepts in which families experience risk factors and the identification of resources used for coping. These concepts have been captured in relation to resilience in Antonovsky's salutogenic model (Antonovsky, 1987; Antonovsky, 1996) and Bronfenbrenner's ecological model (Bronfenbrenner, 1979; Bronfenbrenner, 1989).

A salutogenic model avoids the notion of risk exposure as a prerequisite for being labelled resilient and places the emphasis on positive factors that contribute to health and well being. This focuses on factors that identify the family's coping resources, which may contribute to resilience and effective adjustment. However, the emphasis on resilience in the ecological approach considers the influence of social

context, both proximal and distal, to families (Crnic & Stormshak, 2000). This notion is formalised in Bronfenbrenner's ecological model, which specifies that well being is affected substantially by the social context in which families are embedded, and is a function of the quality of relationships among individuals, family and institutional systems (see Figure 1.1). This study's conceptual framework is based on both the salutogenic and ecological approaches in examining the indicators of resilience of Saudi families with chronically ill children. An explanation of Antonovsky's salutogenic and Bronfenbrenner's ecological models follows and the interrelatedness of these models can be seen in Figures 1.1 and 1.2 below.

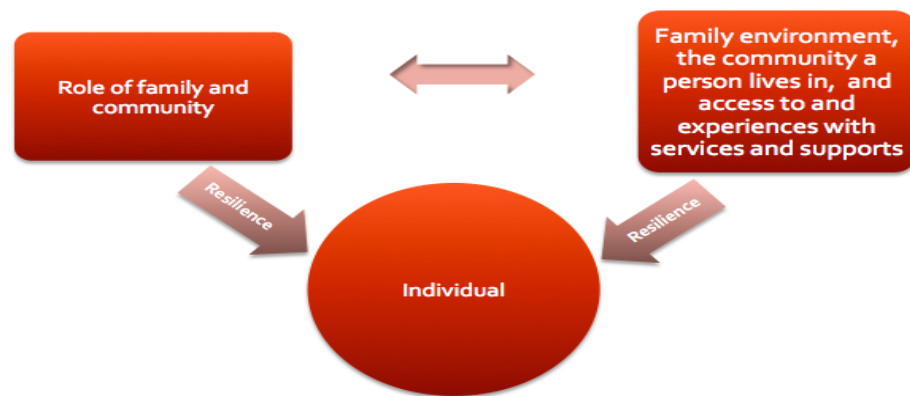


Figure 1.1: Bronfenbrenner's ecological model (1979) (Crnic & Stormshak, 2000).

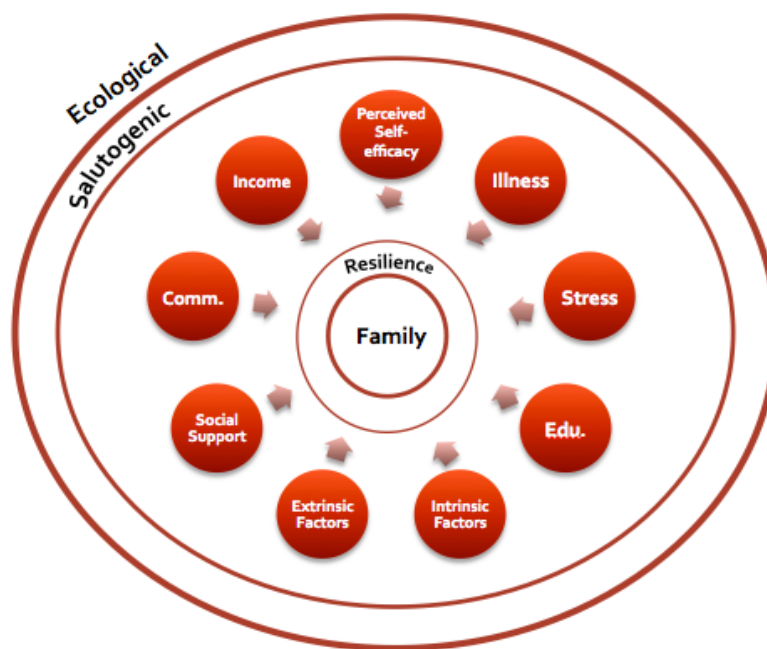


Figure 1.2: Antonovsky's salutogenic and Bronfenbrenner's ecological models.

1.7.1 Antonovsky's Salutogenic Model

Parents facing major crises, such as a child's chronic illness, need to do more than deal with the immediate problem and its emotional effects (Lee, Cohen, Edgar, Laizner & Gagnon, 2006; Suominen & Lindstrom, 2008). They need to learn to deal with parental stress associated with their child's chronic illness and the stress it places on other healthy siblings, otherwise the family unit may disintegrate. Antonovsky (1987) conceptualises coping as a person struggling with everyday stress.

Antonovsky's salutogenic model (1987) was designed to advance understanding of the relationship among stressors, health and coping, with the aim of explaining how some individuals remain healthy despite stressors in their everyday life. Antonovsky proposed that generalised resistance resources (wealth, strength, culture stability, social support) could promote a sense of coherence. Antonovsky's model describes the

substantive structure of the sense of coherence with three components: comprehensibility, manageability and meaningfulness. These develop, as people's experiences are influenced by reliability and balancing, respectively. Unlike concepts such as locus of control, self-efficacy and problem-oriented coping, the coherence model is intended to be a universally meaningful construct that cuts across divisions of gender, social class, religion and culture. The salutogenic model recognises that optimum functioning requires social stability and freedom from anxiety, stress, depression and persecution.

The salutogenic model sidesteps the whole notion of risk exposure as a prerequisite for being labelled 'resilient', and emphasises factors that contribute to health and well being. Antonovsky's salutogenic model focuses on factors that identify coping resources within the family, which may contribute to resilience and effective adjustment, notwithstanding adversity and risk. The concepts implicit in the salutogenic model are emphasised in health promotion practices. While a salutogenic model highlights competence and healthy family functioning in multiple domains (e.g., social, emotional and academic), it also emphasises enhancing protective factors in the lives of all families, irrespective of the risk present. Implicit in this approach is the idea that resilience in families is fostered and promoted by establishing protective factors in the environment (Suominen & Lindstrom, 2008).

Antonovsky focused on the impact of social conditions on people's health in a society and proposed that the key to coping was embedded in society and in people who care about each other. Antonovsky's model is crucial to the current study, as social

influence is very important in the Arab world, especially Saudi Arabia. Hence, it would affect the way Saudi families with chronically ill children choose their coping strategies.

The factors that reside within an individual include a variety of coping skills, for example, self-efficacy. Also worth considering are positive external factors to the individual. These include parental support, adult monitoring and organisations that promote positive development. The term ‘external’ emphasises the social environment and helps place resilience in a more ecological context, moving away from a conceptualisation of resilience as a static, individual trait.

1.7.2 Bronfenbrenner’s ecological model.

Bronfenbrenner’s ecological model was first introduced in the 1970s. It specifies that well being is affected significantly by the social contexts in which families are embedded, and is a function of the quality of relationships among individuals, families and institutional systems. The factors that reside within the individual include a variety of coping skills including: self-efficacy, self-esteem, problem solving, communication and cooperation (Lovat, Clement & Toomey, 2010, p. 414). Factors external to the individual considered protective include: parental support, adult monitoring, or organisations that promote positive development. The term ‘external’ emphasises the effects of a social environment on the child’s health and development, and locates resilience in an ecological context, moving away from a conceptualisation of resilience as a static, individual trait (Lovat et al., 2010, p. 414).

Bronfenbrenner’s ecological theory holds that development is influenced by several environmental systems (McCubbin & McCubbin, 2001). The theory identifies five environmental systems:

- ***Microsystem:*** refers to the immediate surroundings of the individual. This includes the person's family, friends and neighbourhood. It is in the microsystem that the most direct interactions with social agents take place with parents and friends. The individual is not merely a passive recipient of experiences in these settings, but someone who actually helps to construct the social settings.
- ***Mesosystem:*** refers to the relations among the different connections between contexts. Some common examples are the connection between family experiences and friendship experiences, and family experiences to neighbourhood experiences. For example, children whose parents have rejected them may have difficulty developing positive relations with their friends.
- ***Exosystem:*** is concerned with the connection between a social setting in which the individual does not have an active role and the individual's immediate context. For example, a wife's or child's experiences at home may be influenced by the husband's experiences at work. The husband might receive a promotion that requires more travel, which might increase conflict with his wife and affect patterns of interaction with his children.
- ***Macrosystem:*** describes the culture in which individuals live. Culture in this context can be defined as 'the ways of people'. Cultural contexts would include socioeconomic status, poverty and society.
- ***Chronosystem:*** refers to the patterns of environmental events and transitions over the life of an individual, as well as sociohistorical circumstances. For

example, divorce is a significant transition. Researchers have found that the negative effects of divorce on children often peak in the first year after the divorce. Two years later, family interaction is less chaotic and more stable (McCubbin & McCubbin, 2001).

Bronfenbrenner's ecological model is one among many different models related to human development. It emphasises environmental factors as major factors in development.

1.7.3 The study's conceptual framework.

The researcher used an eclectic approach, based on previous models, to create a conceptual framework for this study. This framework is geared towards understanding the effects of chronic illness on the physical, emotional and psychological health of family members. This study's conceptual framework employs a holistic approach when looking at the various levels of relationships between family resilience and the chronic illness of a child.

Chronic illness leads to stress, which affects normal family functioning and structure (Bain, 1998; Barlow & Ellard, 2006; Bellin & Kovacks, 2006). The stress caused by a chronic illness is not the only form of stress experienced by families; it accompanies other forms of everyday life stressors that will affect the health and harmony of family members negatively. When risk factors such as the high income, high education, high self-efficacy, emotional stability, good communication and social support are managed appropriately, then family members remain composed during the stressful period and emerge even stronger and become resilient.

In contrast, low income, low education, low self-efficacy, emotional problems, lack of communication and lack of social support will accumulate and negatively affect family interrelationships and functioning, causing further stress and negative attitudes within the family (see Figure 1.3). Nurses and other health workers should develop clinical intervention strategies to target specific areas that will ensure family members perceive the chronic illness in a healthy manner, and positively manage these risk factors.

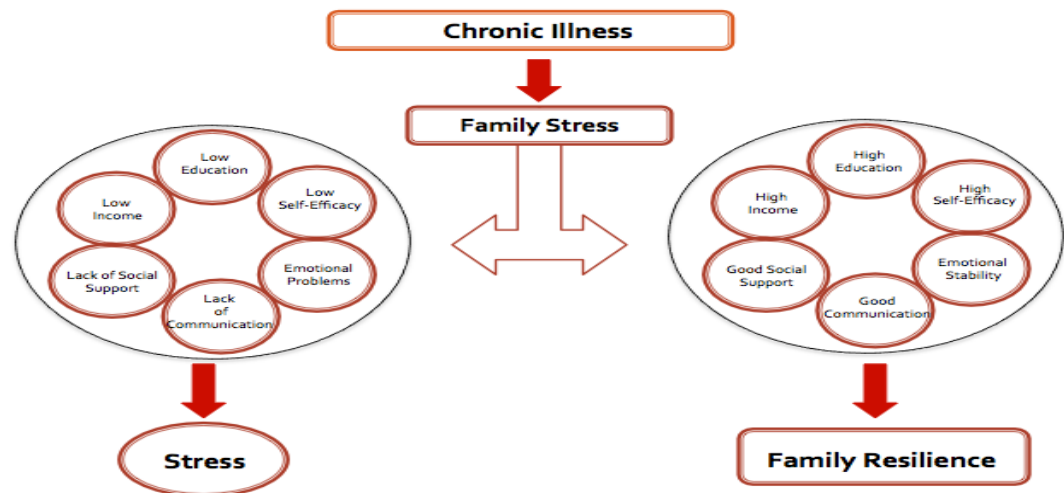


Figure 1.3: The study's conceptual framework.

1.8 Organisation of the Thesis

This thesis consists of eight chapters. Chapter 1, the current chapter, provides a brief introduction and overview of the study. It discusses the background of the study, and gives an overview of the phenomenon of resilience, the rationale, research aims, objectives and questions. A theoretical framework of the study, along with reviews of

the relevant coping models and theories, is also provided. Chapter 2 describes the risk and protective factors associated with families in which a child has a chronic illness. The impact of childhood chronic illness on the family is considered, including family resources, parent functioning and sibling relationships. A discussion of family, community and hospital supports for families of chronically ill children is also provided. Religion and coping, and the influence of culture on coping mechanisms, will also be discussed in Chapter 2. A critique of the literature review relevant to the thesis (that is, resilience literature) is provided in Chapter 3. Chapter 4 describes the methodology of this study, with an overview of the variety of methods employed within the thesis, a brief discussion of the setting, and the study's ethical considerations. Chapter 5 presents analyses of the quantitative data collected from the questionnaire and Chapter 6 presents the analyses of the qualitative data collected from the semi-structured face-to-face interviews. A summary of the major findings and a comparison of these with the literature (to embed the study) are provided in Chapter 7. Finally, Chapter 8 summarises the thesis, its benefits and limitations, conclusions, recommendations and further directions.

1.9 Summary

This research focuses on the responses from Saudi families with a chronically ill child, and their expectations regarding the support they receive from the Saudi healthcare system. Further focus is given to understanding the factors and adversities of everyday life for families in this situation. The study seeks to describe and explore the approaches adopted by Saudi families when faced with a chronically ill child. It is important for families to adopt a resilient approach when faced with the adversity of

having a chronically ill child, to ensure that the family is able to withstand the various challenges it faces when dealing with such a situation. A background and an overview of family and chronic illness in children will be discussed in the following chapter.

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Chapter 2 : Background and Overview

2.1 Introduction

Families in Saudi Arabia are very traditional, with the family unit usually consisting of a mother, father and children. However, the father may have up to four wives (Hassounah-Phillips, 2001) who then make up the extended family structure. The extended family structure also includes uncles, aunts and grandparents. When a child in a family falls ill, it affects the whole extended family and its social network. Behavioural, social, psychological, educational and developmental disorders might eventuate due to a child's chronic illness. These can derail the functioning of the family and have a ripple effect on all the members and affect their relationships with each other (Erdogan & Karaman, 2008; Prug & Eckhardt, 2000). Although such stressors may vary considerably from one person to another, they have a significant impact on the quality of daily life of every affected individual (Ronen, Streiner & Rosenbaum, 2003).

This chapter will provide a general definition of 'the family' and will identify the characteristics and roles of members in a Saudi family. Chronic illness in children will be defined, and a comprehensive overview given of how a child's chronic illness impacts upon the family unit and alters parental and sibling relationships. Finally, the influence of Saudi culture and religion on the physical, emotional, psychological and social support of families with chronically ill children will be outlined. To date, no studies have been reported regarding the consequences of children's chronic illness on families in Saudi Arabia.

2.2 Definition and Structure of Families

Stevenson (2010) defined the family as ‘a group consisting of two parents and their children living together as a unit’ (p. 631). Similarly, Coty and Wallston (2010) reported Craft and Willadsen’s (1992) definition of a family as ‘a social context that is characterised by caring, mutual attachment, long term commitment and responsibility to provide individual growth, supportive relationships’ (p. 519). This definition emphasises the importance of supportive behaviours among family members.

The family is the single most important unit or institution of Saudi society. For Saudis, the family is the primary basis of identity and status for the individual, whose loyalty is first and foremost to the family (Alsaleh, 2012). In the Arab culture, the stereotypical image of the ideal family consists of a father, mother and children. Arab society views this image of two opposite gender parents and children as the ideal family, and many legal systems around the world base their laws on this image of a family (Alkhadhari, 2009). Moreover, marriage is a well-defined institution, where both partners (opposite sex) are given respect, recognition and societal approval to have children (Rashad, Osman & Roudi-Fahimi, 2005). Parenting is the process of taking care of children until they are old enough to take care of themselves. WHO (2007) has defined parents as ‘all those who provide significant and/or primary care for their children, over a significant period of the adolescent’s life, without being paid as an employee’.

A family in the Arab world, in general (and in Saudi Arabia in particular), differs from a family in the Western world in that it includes extended family members. It implies solidarity, social cohesion and mutual support among its members (Jammal,

2001). Families in the Middle East including Saudi Arabia tend to be patriarchal, with the male as the household head (Alsaleh, 2012). An understanding of the structure and role of the members of a Saudi family is valuable to health professionals caring for a chronically ill child and his/her family.

2.2.1 Role of Saudi men.

As mentioned earlier, Saudi families have a patriarchal structure (Alsaleh, 2012; McCabe, Feghali & Abdallah, 2008; Pellegrini & Scandura, 2008), with men being the head and leaders of the family. Their duties are focused outside the household. The father's traditional authoritarian role is described in the literature as being strong, stoic, laying down the rules, restricting the children and bearing responsibility for the family's financial situation (Johansson, Anderzen-Carlsson, Ahlin & Andershed, 2012). As the economic decision maker, the father is an authoritarian figure at the top of a hierarchy. He traditionally has the ultimate power over his wife and children (McCabe et al., 2008; Pellegrini & Scandura, 2008; Sullivan, 2012). This perspective advocates male dominance and emphasises the inferior role of women in the Saudi family structure (Alsaleh, 2012; McCabe et al., 2008; Pellegrini & Scandura, 2008). Saudi men have more social freedom and higher social regard than Saudi women, who tend to share the same characteristics such as class, origin, race, nationality and age (Al-Mohamed, 2008; Alsaleh, 2012).

2.2.2 Role of Saudi women.

In Saudi Arabia, women face several restrictions based entirely on gender. Regardless of age or marital status, a woman is required to have a male guardian who may be her father, husband, brother, uncle, or even her own son (Alkhadhari, 2009; Al-

Mohamed, 2008; Pellegrini & Scandura, 2008). A woman cannot travel, attend university, work or marry without her guardian's permission. Thus, the Saudi woman's quality of life depends entirely on her family, namely the male members. If a woman is lucky enough to come from a modern open Saudi family, she will be educated, encouraged to work if she chooses, and may have a say in who she marries. If she comes from a more traditional conservative family, she may not be allowed to do any of these things (Alsaleh, 2012).

Throughout history, women took the role of caring for ill family members (Johansson et al., 2012). Saudi women are viewed as the primary caregivers in a Saudi family. This includes her household responsibilities (Brown, 2005) of managing the house, taking care of the children, and making decisions regarding the children's upbringing. Women in a traditional Saudi family are not expected to work outside the house (Sullivan, 2012). However, due to the increased self-esteem of modern Saudi women—and partially owing to a desire to contribute to the nation's drive for progress—Saudi women are increasingly willing to assume new social roles (Alsaleh, 2012). Thus, there are Saudi women who currently hold professional positions in media and correspondence, Saudi television, schools, financial institutions and hospitals (Alsaleh, 2012).

The next section will provide a definition of chronic illness in children and a comprehensive overview of how a child's chronic illness impacts the family unit and alters parental and sibling relationships.

2.3 What is Chronic Illness?

The WHO (2012) has defined chronic illness as any disorder that persists over a long period of time and slowly progresses, affecting the physical, emotional, intellectual, vocational, social and spiritual functioning of the individual. Van Cleave, Gortmaker and Perrin (2010) defined chronic health conditions in a child as ‘any physical, emotional, or mental condition that prevents the child from attending school regularly, doing regular school work, or doing usual childhood activities, or that requires frequent attention or treatment from a doctor or other health professionals, regular use of any medication, or use of special equipment’ (p. 624). Chronic illnesses affect people of all age groups worldwide. These illnesses affect the daily functioning of individuals for lengthy periods—often for life—and cannot be cured, requiring long term medical and nursing care (Gamborg, Jensen & Sørensen, 2011; Kuh & Smith, 2005; Mokkink et al., 2008).

Childhood chronic illnesses represent a major challenge and burden for affected families, as well as for the health care system (Omran, Elimam & Yin, 2013). Some significant conditions include: diabetes, cancer, cerebral palsy, epilepsy, Down’s syndrome and other inherited chromosomal anomalies, heart conditions, cystic fibrosis, juvenile arthritis, lung diseases and asthma, dermatitis, eczema and psoriasis, chronic renal insufficiency, leukaemia and various types of anaemia (Theofanidis, 2007). These diseases are the most common reasons for childhood death in all developed and developing countries (Wang, Armstrong & Cairns, 2011).

Chronic illnesses in children, even if well managed, affect their social, psychological and physical development (Omran et al., 2013). In 2005, WHO re-

emphasised the importance of chronic non-communicable diseases as a neglected global health issue. Worldwide, 10 to 15 per cent of children under 16 years of age are affected by chronic long term conditions. The prevalence of children with chronic illnesses varies widely, with an overall rate of 10 to 20 per cent (Janse, Uiterwaal, Gemke, Kimpfen & Sinnema, 2005). This rate is expected to increase further (Omran et al., 2013).

Children with chronic physical disorders have twice the risk of psychosocial maladjustment compared with healthy children. Most children and adolescents with chronic illnesses also have acute symptoms. Some symptoms may go into remission, or not present for some time.

2.4 The Effect of Chronic Illness on Family and Parental Relationships

A chronic illness is a traumatic situation, and families of chronically ill children usually go through three phases when they first encounter this adversity. The first phase is ‘astonishment and refusal’ (Erdogan & Kahraman, 2008; Wise, 2007). Here, the family would like to believe that the diagnosis is wrong; they may also act as if they do not understand the disease and its seriousness. The second phase is ‘anger, indignation and guilt’ (Erdogan & Kahraman, 2008; Wise, 2007), whereby the anger is mostly directed at the treatment team. Feeling guilty is accompanied with such frequently asked questions as ‘why us? why our child?’ Some families may even perceive the disease as a punishment. Acceptance of the disease is the third and final phase (Erdogan & Kahraman, 2008; Wise, 2007). The child and the family may remain in one of these phases, or they may regress to a previous phase. The reaction to living with a chronically ill child varies among families (Santacroce, 2003), depending on the age of

the child, the child's adaptation level and ability, interactions between child, mother, father and other siblings, family balance, seriousness of the illness, pain, medication, and limitations and length of the illness.

Despite all these challenges, parents of chronically ill children report feelings of love, happiness and hope (Ahlstrom, Skarsater & Danielson, 2007; Barlow & Ellard, 2006; Lowes, Lyne & Gregory, 2004). When a child is diagnosed with a chronic illness, the family experiences a range of emotions, such as shock, sadness, fear, nervousness, frustration, anger and sorrow (Sallfors & Hallberg, 2003). Some families are more likely to experience increased stress and vulnerability than other families.

Research suggests that chronic illness changes the way parents and families operate in a range of ways. For instance, Wamboldt and Wamboldt (2000) identified that parents of chronically ill children do not change their general practices or overall philosophy of child-rearing, compared with families of well children; however, many families become more organised and structured as they struggle to manage the stress and demands of a chronically ill child.

Family members are often the primary caregivers for people with a chronic illness (Smith, Greenberg & Mallick Seltzer, 2007). Some common challenges of this role include tension in family relations, time management struggles, disrupted family activities, disconnection from social networks, high medical costs, and difficulties interacting with the children's school (Murray, Kelley-Soderholm & Murray, 2007). Many areas of family life can be affected by a chronic illness, such as daily routines, financial decisions, careers, developmental transitions, friendships, school performance, parenting strategies, and sibling relationships. If the family views the stressors as

unmanageable or they are unable to attain supportive resources, family relationships may weaken and the negative effects of stress may accumulate (Murray et al., 2007).

Parents of a chronically ill child may struggle to meet the demands of parenting. They are constantly required to change their roles and lifestyle. The nature of the disease, the need to manage symptoms, and the complexity of treatment all cause emotional strain that begins with the uncertainty of the child's health condition (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2004). Parents also experience the possibility of separation from their children due to hospitalisation, changes in their parenting responsibilities and role strain (Hopia et al., 2004). One study reported that parents of chronically ill children often become emotionally strained, not knowing what they should do for their child and not being able to take care of the hospitalised child (Hopia et al., 2004). Additionally, responses may include feeling guilty and a decline in self-worthiness (Erdogan & Kahraman, 2008; Wise, 2007). Parents of chronically ill children may become overprotective and overly concerned about their ill child's health (Britton & Moore, 2002; Katz, 2002). Some parents may also experience periods of anxiety or depression.

There are differences in the roles of the mother and father in families with a sick child (Amato, 2005; Mackay, 2005). Mothers mostly undertake the job of nursing the sick child, with fathers assisting. It is more difficult for families in which both the father and mother work. Studies indicate that parents (especially mothers) who have a sick child are under more stress and have higher anxiety levels than those who do not have a sick child (Amato, 2005; Hasting, 2003; Mackay, 2005). Some psychiatric problems,

such as depression and anxiety disorders, are observed more frequently in mothers who have a chronically ill child (Glidden & Schoolcraft, 2003).

According to Drash and Becker (1990), Saudi mothers of diabetic children undergo psychological responses, including initial shock, fear, depression and anger. Various factors that assist families to cope with the illness of the child include the age of the child, the type and the severity of the chronic illness, the availability of medical services and a higher education and economic condition of the parents (Masten & Powell, 2003; Walsh, 2003). Higher socioeconomic status has a positive effect on parents' ability to cope with a chronically ill child, and on the overall activities of the family (Le Blanc, Goldsmith & Patel, 2003).

Chronic illness can lead to disturbed family routines and restricted family activities. Gadze (2011) found that family disruption was a major factor in the adjustment of chronically ill children. According to this study, children with epilepsy reported restrictions in family routine and/or in their own social activities, which has a significant effect on their life and that of the family.

Hovey (2005) established that fathers experience more difficulty forming an attachment with a chronically ill child. Ellenwood and Jenkins (2007) noted that mothers of chronically ill children may become neurotic, introverted, and lack self-confidence, whereas fathers of chronically ill children may develop long term personality changes. Fathers today are caught between the traditional male role and the modern supportive and caring role (Johansson et al., 2012). Modern Saudi fathers who attempt to take on the supportive fatherly role of a chronically ill child are faced with difficulties due to the traditional cultural attitudes that do not support this caring role in

fathers. These difficulties are not helped by the fact that in Saudi health care services do not accommodate fathers. Fathers are only allowed to visit; only mothers are allowed to stay overnight with the child (Alsaleh, 2012).

Family relationships can be greatly affected as a result of a child's chronic illness. For example, one study demonstrated that parents felt stronger emotional responses towards the challenges experienced by their chronically ill child, and did not have the same emotional responses to their other children (Murray et al., 2007). Similarly, due to the many struggles being encountered, some parents noticed that they had disconnected from their partner (Murray et al., 2007). Johansson et al. (2012) stated that families caring for chronically ill children may experience more strains and burdens on their physical and emotional resources. Conversely, Murray et al. (2007) found that family relationships may strengthen as a result of the child's chronic condition. Many families saw the illness as an opportunity for increased communication among family members (Murray et al., 2007). Murray et al. (2007) also argued that in some cases, the child with the chronic illness holds the family together and acts as a diversion for the family, thus avoiding other issues.

Extended family members' relationships may also be strongly affected by the challenges faced when a child has a chronic illness. Family members may question the child's condition and search for explanations, while healthy children may express great curiosity towards the chronic condition and concerns about its cause (Murray et al., 2007). In a study by Fisman, Wolf, Ellison and Freeman (2000), the stress produced as a result of a child's chronic illness was found to have affected parental and marital functioning, and led to behavioural and chronic emotional problems in healthy children.

Likewise, family members may experience ongoing conflicts and somatic illnesses (Ellenwood & Jenkins, 2007).

In addition, Hocaoglu and Koroglu (2011) drew attention to the extensive impact of financial stress associated with caring for a child with chronic illness. Many interrelated issues were raised by families in relation to financial pressure, including increased medical costs, reduced employment opportunities due to caring requirements, and the expense of relocation to often more costly accommodation closer to medical services. Financial pressure was also related to a break down in communication, family sacrifices, supplementary employment to meet financial commitments and disrupted work patterns to keep medical appointments. Researchers have consistently demonstrated that family functioning is a powerful determinant of overall quality of life and well being in children with chronic medical conditions (Herzer et al., 2011). In addition, research has identified families of children with chronic illness as being at significantly increased risk of adverse socioeconomic circumstances (Emerson, Hatton, Llewellyn, Blacker & Graham, 2006). This suggests that these pressures experienced due to financial hardship are likely to be the norm for these families.

Workforce sacrifices can affect a family's income significantly. Consequently, parents of children with a chronic illness tend to have lower than average incomes (Dobson, Middleton & Beardsworth, 2001; Lukemeyer, Meyers & Smeeding, 2000). This is further compounded by the additional costs of raising a child with a chronic illness (Lukemeyer et al., 2000). Dobson et al. (2001) found that it costs between two and three times more to raise a child with a chronic illness than a child without a chronic illness, and this only included 'minimum essential costs'. To meet the expense of having

a child with a chronic illness, parents spend less in other areas, such as on themselves, leisure activities and holidays.

Social isolation is a further problem experienced by some families with a chronically ill child, because of financial, time and respite limitations, as well as a loss of previous social networks and stigma (Dobson et al., 2001; Patterson, 2002). Parents who have a child with a chronic illness might be unable to connect with other people. Parents also are likely to experience more stress, lower levels of marital satisfaction, poorer mental health and lower levels of well being than other families (Gardner & Harmon, 2002; Patterson, 2002). Other family members' lives may also be affected. If support is inadequate, parents may have less time and energy for other family members, and siblings may be expected to share some of the caring responsibilities (Amato, 2005).

Home care and respite care services for chronically ill children may have positive effects on the family. A controlled longitudinal study of outcomes for families using respite care found increased optimism in caring for children at home, along with reduced parental stress (Bruns & Burchard, 2000). However, the benefits to the family provided by respite care are often short term. For instance, mothers using respite summer camps for their chronically ill children reported reduced anxiety, depression and distress, but in one study the effects lasted for only one month after the camp finished (Meltzer & Johnson, 2004). The literature highlights several problems with respite care, which prohibits longer term benefits. Family members reported feelings of discomfort with carers intruding into their home environment in home care and respite care services (Valkenier, Hayes & McElheran, 2002). There are also inequities in the provision of respite care to families, such as a bias in uptake of services by articulate middle class

families, and children with challenging behaviours being excluded from respite care (McGill, Papachristoforou & Cooper, 2006).

2.5 Effect of Chronic Illness on Sibling Relationships

Numerous researchers have documented the impact of a child's chronic illness on siblings. Foster et al. (2000) found that siblings can be both directly and indirectly affected by living with a brother/sister who has a chronic illness. In many cases, this may cause resentment between the siblings. Based on the physical and emotional demands placed on parents as a result of the chronic illness, differential treatment of siblings is not uncommon.

Furthermore, siblings of chronically ill children have difficulty in their relations with and adjustment to, the ill child. In addition, some experience negative emotions, such as jealousy, due to all the attention being given to the ill sibling (Prchal & Landolt, 2012). Prchal and Landolt also found that the psychological distress of parents—expressed as being sensitive, irritable, burdened or weak—was difficult for siblings. In some families, this resulted in role changes. Further, in a cross-sectional study looking at the impact of chronic illness on children, healthy siblings and mothers, Foster et al. (2000) found the expectations of good behaviour were raised for healthy siblings and that parental tolerance for misbehaviour was lowered.

Similar to Foster et al.'s (2000) findings, a study conducted by Weiss, Schiaffino and Ilowite (2001) considered how sibling relationships developed under the strain of a chronic illness. These researchers found that sibling relationships are essential, because they are foundational to how a child will develop and maintain other close relationships later in life. Children with a solid support networks of family and friends surrounding

them also have a more positive view of themselves (Weiss et al., 2001). However, when a child suffers from a chronic illness, sibling relationships may be altered or strained because a chronically ill child is perceived as needing more protection and attention to survive. Findings from this same study also showed that other risk and resistance factors associated with sibling involvement include: age, gender, birth order, functional loss, parental distress and dysfunction, family social support, child perceptions of competence, cohesion and coping (Weiss et al., 2001). Moreover, Hollidge (2001) found that the psychological growth of the healthy sibling may be affected if a chronic illness brings stress to the sibling relationship. In addition, Ellenwood and Jenkins (2007) noted that healthy siblings may feel abandoned by their parents, become resentful, and pick fights with peers or other siblings. Similarly, Hollidge (2001) conducted a study that examined the psychological adjustment of healthy siblings living in the same house as a chronically ill child. In this study, it was found that healthy siblings actually had the greatest amount of stress to a sibling's chronic illness. The author of this study argued that this greater level of stress was due to the healthy child's demands and needs for parental attention and affection not being met. Hollidge (2001) found that in an attempt to gain this valuable attention, parents reported that healthy children may feign an illness, ask for medication, and engage in disruptive behaviours to receive some parental attention.

To illustrate how a chronic illness can affect a healthy sibling, Hollidge (2001) used a semi-structured interview to evaluate factors such as emotional isolation, resentment towards the chronically ill sibling, exaggerated sibling rivalry, and a strong sense of responsibility. Results indicated that the healthy sibling was at a higher risk of

developing depression, anxiety and low self-esteem. Healthy siblings were more likely to experience psychosomatic symptoms, such as: difficulties with social isolation, poor communication with parents, and a sense of responsibility and resentment towards their ill sibling (Hollidge, 2001). Further, sibling relationships in which one sibling has a chronic illness are more complex and tend to be affected by many variables, including age, socioeconomic status, severity of illness, birth order and care-taking responsibilities (Weiss et al., 2001).

Additionally, when taking a closer look at healthy children, Hollidge (2001) found that these children appeared highly capable and competent in the external world; however, their emotional health could be unstable. Hollidge also found that many healthy children suffered from high amounts of anxiety that stemmed from worry, guilt, shame, and competitive feelings with their chronically ill siblings. These feelings of guilt and shame originated from the negative feelings that a healthy child may feel towards the chronically ill sibling. Upon further examination, Hollidge indicated that the healthy participants stated they were unable to share these negative, and often aggressive, actions with anyone and instead fantasised with their friends or family. Moreover, the study also revealed that healthy siblings internalised their difficulties and worries and were unable to share these worries with others. The healthy siblings also reported feelings of unhappiness and jealousy in relation to their sick sibling (Hollidge, 2001).

In another study, Smith, Greenberg and Mallick Seltzer (2007) discovered that siblings could identify and describe one or more personal strengths that developed as a result of coping with the challenges of having a sibling with a chronic illness. These

authors stated that many of these strengths included enhanced coping skills, increased personal competence, greater appreciation of the sibling's life and well being, and a strengthening of family bonds. Further, the healthy sibling became more sensitive to people with disabilities, made new friends, and had a greater appreciation for a person's inner strengths (Smith et al., 2007).

In contrast, Weiss et al. (2001) found that in some cases, chronic illness may cause siblings to grow closer, as they tended to be more isolated from the community and cared for each other. Even so, the reverse may also happen when they have little in common and identified less with each other because of a decreased sense of closeness (Weiss et al., 2001).

In a meta-analytic review of randomised studies, Martire, Lustig, Schulz, Miller and Helgeson (2004) uncovered some of the negative side effects that may occur due to a sibling's chronic illness. These include poorer physical health and psychological well being, caregiver burden, and a decreased relationship quality with the sibling. Cuskelly and Gunn (2006) also found it was common for parents to disregard the healthy child's efforts and attempts to contribute to the family. When this occurs, the child could become resentful and aggressive. According to Cuskelly and Gunn, male siblings were more likely to avoid a chronically ill female child. It also appeared that male siblings had lower self-concept scores, high anxiety, and extreme feelings of guilt, which could result from an elevated sense of hostility and aggression towards the sibling with a chronic illness (Hollidge, 2001).

Overall, there are many questions that arise regarding sibling relationships and future sibling involvement. Smith et al. (2007) pointed out that a number of factors go

into predicting how siblings will respond to each other later in life. For instance, healthy siblings may be socialised to help care for their chronically ill sibling if they were living at home when their sibling was first diagnosed. In addition, the nature of the sibling relationship determines how involved siblings will be with each other. If the sibling relationship has equal amounts of giving, receiving and support, a healthy sibling will be more inclined to be actively involved with their chronically ill sibling. Similarly, siblings who are younger in age and married were more likely to provide help and support in areas including daily living tasks, transportation and household chores.

Additionally, multiple factors have been identified as possibly limiting sibling involvement. These include severity of the illness, geographic distance, family and work demands, and personal health problems (Smith et al., 2007). It is important to note that sibling relationships are extremely complex and can be affected by any number of variables, not only health (Weiss et al., 2001). However, no matter which way one looks at it, sibling relationships play crucial role in one's development.

2.6 Factors and Stressors Faced by the Family of the Chronically Ill Child

The diagnosis of a child with chronic illness leads to various changes and adjustments within the family that have diverse effects. The effects can be divided into physical, psychological, emotional and financial strains. Families of chronically ill children are subjected to many risk factors and circumstances related to negative psychological outcomes. Some common risk factors that families are at risk of experiencing when dealing with a chronically ill child include: tension in the family, domestic violence, physical abuse such as violence towards a child, emotional abuse,

neglect from busy parents, imbalance in caregiving and discipline when growing up, too many changes in home environment or location, loss of a parent due to death or separation, child's chronic illness, repeated hospital admission, bad influence of sibling behaviour, substance abuse by any family member, socioeconomic marginalisation, community violence, lack of proper community support and professional help in the period of crisis and poverty (Amato, 2005).

Numerous studies have specified several risks for families linked specifically to their child's situation, such as parental divorce, single parent families, large families, and family breakdown (Amato, 2005; Douglas, 2004; Mackay, 2005; Mooney, Oliver & Smith, 2009). There are also other risk factors—as mentioned in Antonovsky's salutogenic and Bronfenbrenner's ecological models—that can affect an individual. These include physical, emotional, cognitive, spiritual and environmental issues (McCubbin & McCubbin, 2001). Further, resilience is affected by different factors. These include perceived self-efficacy, illness, stress, communication, social supply, intrinsic and extrinsic factors, education and income (McCubbin & McCubbin, 2001).

Stress is part of life, and it affects everyone at one time or another. Nowadays, Saudi families have worries and concerns dealing with a number of issues in their lives. These include relationships, major life events, job related issues (difficulty in concentration, career concerns, retirement planning, balancing home and work), financial concerns, family and parenting issues (single parenting, parent-child relationships, communication problems, raising children), marital concerns (separation, divorce, communication problems), social responsibilities (child care, housework, care of older relatives), health issues, behavioural concerns (compulsive behaviours,

smoking, eating disorders, lying, overspending), and personal concerns (mood swings, depression, sleep disturbance, social isolation, aimless future, lack of confidence). In some instances, the medications provided to a child with a chronic illness might have serious side effects that can affect the perception of family members negatively. Lack of proper coping strategies and the fear and anxiety created by the situation is bound to affect both parents and siblings of the ill child (Walsh, 2006). The parents might blame themselves for the illness, especially when it is a genetic disease. The siblings might feel neglected, especially when the parents invest most of their energy on the chronically ill child.

Physical stress maybe experienced when the child is treated at home, and parents and well children are compelled to act as caregivers. When the chronically ill child is completely incapacitated and cannot perform activities such as bathing, going to the bathroom or feeding, parents will be forced to assist the chronically ill child. The physical exertion involved as a result of having to perform tasks, additional to their regular daily tasks, can be overwhelming and stressful (Monroe, 2008). In some situations, the family members are forced to wake up during the night to rush the chronically ill child to hospital, to give medicine or just to check on how the child is doing. This prolonged physical stress can be translated into emotional and psychological stress (Walsh, 2006). The psychological stress is a result of constant worrying about the outcome of treatment, and not being able to deal effectively with the uncertainties characteristic of some chronic illnesses.

Emotional stress usually develops due to the inability of family members to handle fluctuating emotions in each other effectively. Emotional stress can affect the

relationships of family members where some individuals may seclude themselves from activities, instead of strengthening each another (Masten & Powell, 2003; Walsh, 2003). The effects on family members are often interrelated, and one aspect might quickly develop into another when proper interventions are not adopted.

2.7 Influence of Culture on Coping Mechanisms

Understanding culture provides guidelines for standards of behaviour in the presence of disease (Doumit, Huijer & Nassar, 2010). Culture refers to a set of contexts, structures, values, traditions and ways of engaging members within a society and is transmitted across generations through social learning (Richerson & Boyd, 2005). The definition of culture is typically broad, which makes it difficult to decide how culture can be included in empirical work. Therefore, psychologists have proposed features of cultures to be used as organising constructs. The most commonly used constructs to account for observed cultural differences and similarities are individualism and collectivism (Kim & Sherman, 2007), which have been particularly useful for understanding how people view themselves and their relationships with others. It is useful especially in this study, that relates to health and illness experiences. The consequences for a Western family of a chronic illness diagnosis in children are well documented, and involve a range of emotional, social, physical and spiritual difficulties that family members may face (Emerson et al., 2006; Graungaard & Skov, 2007).

Within individualistically oriented cultures, such as the United Kingdom and the United States of America, the main model of the self is one of independence, characterised by self-defining attributes and self-expression (Kim & Sherman, 2007). This might apply to Australia as well, as these three countries share similar cultural and

educational influences. In these cultures, people are responsible for their own decisions and actions, and relationships can be freely entered into and left. Moreover, in individualistic cultures, people focus on the positive outcomes they wish to achieve, rather than the negative outcomes they wish to avoid (Adams, 2005; Lee, Aaker & Gardner, 2000).

In contrast, in collectivistic cultures such as in East Asia and the Middle East, the main model of the self is interdependent, embedded within the social context and defined by social relationships in groups (Kim & Sherman, 2007). This might apply to Saudi Arabia. People are seen as relational, and their decisions and actions are regarded as being heavily influenced by mutual obligations; relationships are less voluntary and can be more difficult to leave (Adams, 2005; Oyserman, Coon & Kimmelmeier, 2002). Moreover, in collectivistic cultures, individuals are motivated to fit in with the group and maintain social harmony; members focus on their responsibilities and obligations and avoid behaviours that may cause social disruption and disappoint others (Oyserman et al., 2002). Members of these cultures also tend to focus on the negative outcomes they wish to avoid, rather than the positive outcomes they wish to achieve (Lee et al., 2000; Lockwood, Marshall & Sadler, 2005).

To explain different examples of the collectivistic orientation, Merrell, Kinsella, Murphy, Philpin and Ali (2004) examined the impact of chronic illness on children in Bangladeshi families. This study reported that family members viewed providing care and support to the chronically ill child and each other as a positive experience and as a characteristic of ethnic identity. These families reported feeling privileged, lucky and satisfied when taking care of their child. However, in White, Richter, Koeckeritz, Lee

and Munch's (2002) study, South Korean families reported a taboo towards expressing emotional distress linked to chronic illness. In other words, in the South Korean culture, serious chronic diseases are viewed as a source of shame and a consequence of terrible things done in a previous life (White et al., 2002).

In Arab countries, chronic illness is viewed as a long term disorder that causes havoc in the victim's life (Doumit et al., 2010). It is therefore increasingly important to understand the issues surrounding families of children with serious illnesses in the Arab countries, and in particular, the effect on parents and other family members (Graungaard & Skov, 2007). Entwined within the Saudi cultural framework is an elaborate network of perceptions, attitudes and behaviours derived from culture and religion, which determine specific perceptions of illness. In Saudi societies, shared concepts, rules and regulations are underlined, and are expressed in the way people live. Furthermore, understanding the interplay among themes, such as coping strategies, faith, body image and identity can highlight innovative ways of addressing and approaching illness. It is important to understand the coping mechanisms of Saudi families to assist health care professionals establish appropriate ways to support those with chronically ill children.

2.8 Religion and Coping

Coping is both culturally and religiously specific. Religious practices and beliefs are important to people in many countries around the world (Koenig & Larson 2001). Religion plays an important role in helping patients and families cope with serious chronic illnesses. Patients who use religion appear to cope better with their illnesses (Koenig & Larson 2001) and may be able to integrate overwhelmingly negative and stressful experiences into their current worldviews, so that their world remains safe and

predictable. Failure to achieve such integration can result in either depression or post-traumatic stress disorder (Koenig & Larson 2001). When patients and their families already use religion for coping, helping them explore these practices may strengthen their coping abilities.

Religion as a method of coping can be operationalised in different ways. Many studies have assessed the frequency of visiting religious places of worship, or the frequency of prayer, with the assumption that these behaviours were a response to the stressors in question (Harrison, Koenig, Hays, Eme-Akawari & Pargament, 2001). Muslims have practised meditation techniques such as having trust and faith in God, praying, reading the Holy Qur'an (which they call 'the medicine of the heart'), listening to religious broadcasts, believing in an afterlife and visiting places of worship (Abu Raiya, 2008; Ai, Peterson & Huang, 2003). The problem with this assumption is that global measures of religious involvement may reflect dispositional religiousness rather than how people draw on religion during a crisis (Darnell, Chang & Calhoun, 2006).

Most of the research on religious coping has focused on Western adults facing major medical illness or serious trauma. Yet, chronic illnesses pose profound physical and psychological challenges. Religion is a way to cope with these challenges (Zaza, Sellick & Hillier, 2005). Empirical studies have revealed that many people look to their faith when coping with critical life situations. For example, a national survey of Americans shortly after the 11 September 2001 attacks revealed that 90 per cent reportedly returned to God for support (Schuster et al., 2001).

Part of religion's power lies in its ability to serve many purposes for people coping with major life stressors. Murphy, Johnson and Lohan (2003) studied 138

parents who had suffered the violent death of an adolescent or young child, in an attempt to identify factors associated with their ability to find meaning in the deaths five years after the incident. Religion emerged as one significant predictor. Parents who turned to religion to help them cope reported they were able to find greater meaning in their child's death.

In a stressful situation, religion can provide people with a sense of belonging, connectedness and identity. In a study of a community sample in the San Francisco Bay (USA) area, Wink, Dillon and Larsen (2005) found that high levels of involvement in religious institutional life buffered the effects of depression associated with poor physical health, even after controlling for general social support. The researchers suggested that religiousness provided people with not only church-based support, but also a strong and historically based sense of identity and values. Similarly, Hebert, Dang and Schulz (2007) conducted a longitudinal study of depression and grief among family caregivers to loved ones with dementia. They found that higher levels religiousness (e.g., prayer, church attendance, faith) among caregivers at baseline predicted lower levels of depression at follow up.

Religion plays an important role in the context of the research reported in this thesis. More specifically, Saudi Arabia is a deeply religious country where Islam has a great influence on people's daily lives. The absolute majority of Saudis (100 per cent) are Muslim and are attached to the values, norms and moral standards stipulated by Islamic teaching. Islam is central to this study because of the religious practices and experiences of Saudi families with chronically ill children, and because religion is accepted as a common way to cope with these challenges (Zaza et al., 2005).

Few empirical studies on religion among Muslims have been published, and very few have examined the role of Islam with respect to physical and psychological well being. For example, Kamal and Loewenthal (2002) examined the impact of religious-cultural tradition on the suicide related beliefs of 40 young Hindus and 60 Muslims living in the UK. They found that Muslims endorsed moral considerations (e.g., 'my religious beliefs forbid it') more strongly than Hindus. The authors noted that the condemnation of suicide within Islam is reflected in the beliefs of young Muslims.

Among some groups, religion is the most common coping resource. Loewenthal and Cinnirella (1999) studied the views of 59 women from different cultural-religious groups in Britain (Christian, Hindu, Jewish and Muslims) regarding the efficacy of different forms of help for depression and schizophrenia. The study found that prayer was most often seen as being helpful by all the different groups. Most of the Muslims considered prayer as very effective in treating depression. According to Loewenthal and Cinnirella (1999), some of the Muslims' responses regarding prayer included: 'prayer saves me from going into deep depression' (p. 495), 'if you pray you will suffer less' (p. 496), and 'it does not matter how depressed you are, if one can divert your attention towards prayer your low feelings can disappear ... giving all problems to God and having faith in him is very therapeutic' (p. 498).

Similarly, Ai et al. (2003) collected information about religiousness, war-related trauma, religious-spiritual coping, optimism and hope from a sample of 138 Muslims who had escaped from Kosovo and Bosnia and settled in the USA. These authors found that optimism was positively associated with positive religious coping, which in turn was related to increased religiousness and higher education. Further, hope was

positively related to education and negatively associated with negative religious coping. In turn, this was predicted by more severe trauma.

Al-Sabwah and Abdel-Khlek (2006) examined the relationship between religiousness and death distress (for example death anxiety, death depression, and death obsession) among a sample of 570 Egyptian female nursing undergraduates, mainly Muslims. They found that higher levels of religiousness were tied to lower levels of death anxiety and death depression.

As religion plays an important role in the Saudi context, there are many Ahadith (traditions of Prophet Mohammad, *peace be upon him*) that encourage Muslims to seek medical treatment. For example, Abu Hurayrah narrates that the Prophet (*peace be upon him*) said: ‘There is no disease that God has created, except that He also has created its remedy’ (Bukhari 7.582). Taking good care of one’s health is considered by the Prophet Mohammad (*peace be upon him*) to be the right of the body (Bukhari 7.582). The Prophet (*peace be upon him*) not only instructed sick people to take medicine, but he himself invited expert physicians for this purpose (As-Suyuti’s, 1994, p. 125).

The Prophet Mohammad (*peace be upon him*) stated, ‘God has created a cure for every illness except death’ (Bukhari 7.582). Therefore, every Muslim should have faith and trust as an essential part of their belief and should believe that problems, illnesses and life’s troubles will be easy to cope with through such trust and belief in God. When they do this, they will feel happy and hope that God will reward them for their gratitude.

From an Islamic perspective, when people are faced with distress, harm, worry and anxiety, they should try to resist them as much as they can and be patient. As a result, they will gain benefits such as becoming resilient and developing strong

willpower and patience, which will reduce feelings of distress. Thus, their anxiety will be replaced with joy and the hope of blessings and reward from God. As Prophet Mohammad (*peace be upon him*) stated, ‘Everything that happens to a person is good, and this does not apply to anyone except the believer. If something good befalls him/her, he/she gives thanks for it, and that is good for him/her and if something bad befalls him/her, he/she bears it with patience, and that is good for him/her as God will always be there for them’ (Bukhari 7.582).

Although religion is generally a helpful coping strategy, it may also contribute to higher levels of stress. Fitchett et al. (2004) stated that major life events can shake or shatter the individual’s most fundamental beliefs and values, including religious beliefs and values. When this occurs, the individual is likely to experience a period of religious struggle, a time of tension during which question and conflict centre on spiritual matters. There are three types of religious struggles: interpersonal struggle that involves tensions and conflicts with friends, family or church around spiritual issues; intrapersonal struggle that embodies questions and doubts about matters of faith, as well as internal conflicts between higher and lower aspects of oneself; and divine struggle that focuses on negative emotions towards God, including anger, anxiety, fear and feelings of abandonment (Fitchett et al., 2004; Pargament, Koenig, Tarakeshwar & Hahn, 2001).

Religion is an influential coping resource for many people, and a burden for others. In either case, religion is an integral, rich and multidimensional part of the coping process.

2.9 Development of the Health Care System in Saudi Arabia

Health services in Saudi Arabia have improved significantly in recent decades (Walston, Al-Harbi & Al-Omar, 2008). The first public health department was established in Makkah in 1925, based on a royal decree from King Abdulaziz (Alharthi et al., 1999; Almalki, Fitzgerald & Clark, 2011). This department was responsible for monitoring and sponsoring free health care services for the Saudi population and pilgrims by establishing a large number of hospitals and clinics. The next important advance was the establishment of the Ministry of Health (MOH) in 1950, under another royal decree (Alharthi et al., 1999; Almalki et al., 2011). Twenty years later, five-year development plans were introduced by the government to improve all sectors of the nation, including the Saudi health care system (Mufti, 2000). Since then, substantial improvements in all health sectors have been achieved in Saudi Arabia. In 2002, the Council of Health Services, headed by the MOH and including representatives of other government and private health sectors, was established by another royal decree. This was done with the aim of providing the population with up-to-date, equitable, affordable, organised and comprehensive health care (Walston et al., 2008). The aim of the Council was to develop a policy for coordination and integration among all health care service authorities in Saudi Arabia. Significant progress has been achieved in this area (Alkhazem, 2009).

The Saudi MOH is responsible as a government agency for the supervision of health care in public hospitals, private hospitals, clinics, primary health care clinics, first aid centres and ambulance services (Mitchell, 2009). It is also responsible for all health care sectors, such as strategic health planning, initiating and implementing health

policies, and conducting health promotion programmes for Saudi and non-Saudi residents across KSA (Aldossary, While & Barriball, 2008).

The hospital system is classified according to the type of health service and is managed by a variety of governing bodies. The principal body is MOH, which manages all hospitals. Saudi Arabia is divided into 18 health regions, each with a regional director who is attached to the MOH (Aboul-Enein, 2002). The MOH incorporates 70 per cent of the main government hospitals (MOH, 2011). In these hospitals, medical services are provided free of charge for Saudi citizens. The MOH is considered the health care leader in planning, managing and regulating the health care sector (MOH, 2011; Mufti, 2000). The other government hospital sectors include the Ministry of Defense and Aviation (Armed Forces Hospital in Riyadh and Jeddah), the Ministry of Interior and the Saudi Arabia National Guard. These three sectors represent 13 per cent of the total number of hospitals and 21 per cent of hospital beds in the country. The private sector has 26 per cent of hospitals and 16 per cent of beds. Private hospitals are for-profit health organisations that are managed and run independently, often by international cooperatives such as Saudi German Hospital and Saudi British Hospital. These private hospitals are supervised in regard to health regulations by the MOH (Mufti, 2000).

To improve the quality of health care services and to meet the challenges of the Saudi health care system, the MOH has set a national strategy for health care services. This strategy was approved by the Council of Ministers in 2009. It focuses on diversifying funding sources, developing information systems, developing the human workforce, activating the supervision and monitoring role of the MOH over health

services, encouraging the private sector to also contribute in providing health services, improving the quality of preventive, curative and rehabilitative care, and distributing health care services equally to all regions (MOH, 2011).

The health system infrastructure in Saudi Arabia provides health services through the three main health sectors outlined above, with some changes in the total percentage of health care provided as follows. The MOH is the major government provider and financier of health care services in Saudi Arabia, with a total of 251 hospitals (34,450 beds) and 2,109 primary health care centres (PHC) (MOH, 2011). These services comprise 60 per cent of the total health services in Saudi Arabia (MOH, 2011). Other government health agencies provide 20 per cent of services. These agencies include the Ministry of Defense, at eight per cent (e.g., Security Forces Medical Services, Army Forces Medical Services, Royal Commission for Jubail and Yanbu Health Services), teaching hospitals, at seven per cent (e.g., Ministry of Higher Education Hospitals, School Health Units of the Ministry of Education and the Red Crescent Society), national guard hospitals, at three per cent (e.g., National Guard Health Affairs) and others, at two per cent (e.g., King Faisal Specialist Hospital and Research Centre, ARAMCO Hospitals). A total of 21 hospitals (12.17 per cent of beds) are for gynaecology and obstetrics and (14.15 per cent of beds) for paediatrics. The private sector provides the remaining 20 per cent of the total health care offered in Saudi Arabia and contributes to the delivery of health care services, especially in cities and large towns, with a total of 130 hospitals (13,298 beds) (MOH, 2011).

2.10 Psychosocial and Physical Support for Families of Chronically Ill Children

Parents are the most important support for a chronically ill child. Yet if parents are to be able to bear the strains this involves, they must also have support. Having a good, cooperative relationship with the people treating their child is absolutely decisive. This is not only essential for the child to get good medical treatment, but also for the parents' emotional mastery of the situation.

Many support services are available in Saudi for chronically ill children, such as hospital social workers, health care professionals, the social security office, educational psychology services or practical aid services. However, some families are not aware of the support services available to them and end up dealing with the stressors by themselves (Longaretti, 2008). Parents have different experiences with the people helping them. Some find that, in addition to the strains of the chronic illness, they have to use a lot of energy acquiring information and getting in touch with support services, or they find the contact they have does not help them. Some parents find it an exhausting struggle to get anything from health care agencies, so that they give up without getting the help they need (Longaretti, 2008).

Saudi families solve their problems in different ways and have varying needs for help and support. The aim of the following section is to investigate the type of support Saudi families with chronically ill children receive from their family, the community, the health care system and health care professionals.

2.10.1 Support services provided by the Saudi Arabian health care system for chronically ill children.

Health services in Saudi Arabia have improved significantly in recent decades (Walston et al., 2008). The Saudi Arabian government has given high priority to the development of health care services at all levels: primary, secondary and tertiary. However, a number of issues pose challenges to the health care system, such as the shortage of Saudi health professionals in general, and nurses in particular; the fact that the health ministry has multiple monitoring health roles, yet does not have the professional health leaders to fulfill these roles at a high standard; the fact that the MOH has high public demands resulting from the free services provided; and the lack of an accurate national health information system (Aldossary et al., 2008; Walston et al., 2008).

Technological advances have dramatically improved survival rates for children with life-threatening conditions caused by congenital anomalies, disease or injury (Bramlett & Blumberg, 2008). As a result, the number of Saudi children living with chronic illness is growing, and the vast majority of these children live at home with their families (Al-Qurashi et al., 2008). A trend towards earlier discharge of children from hospitals and rehabilitation facilities to outpatient or home health care also exists. Thus, primary care clinicians are increasingly expected to coordinate the care for chronically ill children (Bethell, Read, Blumberg & Newacheck, 2008; Bramlett & Blumberg, 2008).

Many medically fragile Saudi children who require complex care are receiving that care at home. Home care is viewed as more cost-effective than institutional care

(Benedict, 2008; Wang & Watts, 2007). The result is that families are required to perform care that used to be provided by hospital staff (Antonelli et al., 2008; Shattuck & Parish, 2008). More families will be asked to care for chronically ill children at home as the family-centred care model adopted by paediatric hospitals is extended into the home (Hintz, Kendrick, Vohr, Poole & Higgins, 2008; Inkelas, Garro, McQuaid & Ortega, 2008; Shattuck & Parish, 2008). Caring for these children at home places additional strain on daily family life for Saudis. The medically fragile child's 'special' routine and health care needs must be incorporated into the family's normal routines of work, school, transportation, child care and housekeeping (Hintz et al., 2008; Inkelas et al., 2008).

As already mentioned, to improve the quality of health care services and to meet the challenges of the Saudi health care system, the MOH has set a national strategy for health care services. This strategy was approved by the Council of Ministers in 2009. The strategy focuses on diversifying funding sources, developing information systems, developing the human workforce, activating the supervision and monitoring role of the MOH over health services, encouraging the private sector to take its position in providing health services, improving the quality of preventive, curative and rehabilitative care, and distributing health care services equally to all regions (MOH, 2011).

Saudi parents and family members need support. The MOH has provided Saudi families of chronically ill children with many services, such as providing free health care and all medical treatments (e.g., hospitalisation, medications, monthly payment salary, home health care). However, they have not filled the gap of providing emotional

and social supports for these families. Such support for family members has lagged behind (Jannadi, Alshammari, Khan & Hussain, 2008).

KSA has witnessed a dramatic improvement in socioeconomic development in the past 30 years, with notable progress having been made in the development and planning of infrastructure, technology, education, health, housing and the environment. The broader society has changed as a consequence. More women are working, families are moving from one city to another, the youth are more educated (Alsaleh, 2012). Despite all of these improvements and achievements, the Saudi health care system faces many challenges due to the changing constructs of Saudi society. These challenges require new strategies and policies to be implemented by the Saudi MOH. The MOH may provide monetary assistance to families with a child suffering from a chronic illness, but they do not provide enough emotional and social support services for these families. This has the potential to lead families into anxiety, stress, depression, anger, helplessness, confusion, fear, disappointment and many other emotional problems, which will certainly have an impact on all members of the family.

2.10.2 Social and emotional support.

People integrate into a society through their relationships with others; these relationships create personal networks. Agneessens, Waeye and Lievens (2006) explained that the personal network consists of all others with whom a person has various connections, and the most significant form of connection is providing social support. A personal network includes intimate relationships, friendships and neighbourhood or community contacts. Many Western studies have shown the importance of an individual's social support network on stress, psychological, physical

well being and health (Folkman & Moskowitz, 2004; Ptacek & Pierce, 2003). Social support has been shown to mediate and moderate the negative effects of stressful events and continuous challenges (Folkman & Moskowitz, 2004; Ptacek & Pierce, 2003). The potential of social support to reduce stress and assist in coping has been broadly discussed in previous studies (Hobfoll, 2002).

Saudi families with healthy support networks have more access to models of suitable parental behaviour (Walston et al., 2008). In addition, they have more friends, family members or neighbours who may be willing to act as alternative caregivers, or to provide additional support or nurturance to both parents and child. Social support can take many forms, including emotional, practical, decision-making or problem solving assistance, and support related to self-esteem (Muhlbauer, 2002). This support can be provided by family members, relatives, friends, neighbours, school, colleges, health care professionals, religious institutions and other community groups and organisations.

Strong family relationships are vital (Luthar, 2006), and support from extended family members such as aunts, uncles and grandparents has also been consistently associated with protection against the negative effects of having an ill person in the family (Luthar, 2006). Support beyond other family members is a particularly important factor promoting resilient outcomes in the face of stress and adversity. Consequently, emotional support is a basic provision of close personal relationships and is an important determinant of satisfaction within these relationships (Cunningham & Barbee, 2000). It is an exchange through communication. This support conveys the information that one is loved and cared for, respected and valued, and a member of a mutual obligation network (Burleson, 2008). Emotional support involves providing care, empathy, love

and trust (Coffman & Ray, 2002). This includes gestures of comforting, such as demonstrating that an individual is available when needed (Coffman & Ray, 2002), and physical attendance is not always needed (Finfgeld-Connett, 2005). Emotional support can also include sending cards or flowers (Gurowka & Lightman, 1995) or prayers from others (Hupcey, 2001). Other methods also include using the internet (Tichon & Shapiro, 2003) through an email or Facebook, and telephone (Chien-Huey Chang & Schaller, 2000) to provide emotional support.

Perceptions of emotional support have been found to play a critical role in the development and maintenance of friendships, romances, families and work relationships (Burleson, 2008). When emotional support is provided skilfully (i.e., addresses a distressed person's feelings in a sensitive and effective way), it can yield numerous benefits for the recipient, including improvements in emotional states, coping, and even health (Burleson, 2008; Wills & Fegan, 2001).

2.10.3 Physical support.

The provision of providing services or help to families with a sick child, or to others, is physical support. It is the most direct type of social support and is comprised of assistance in many forms, such as providing financial aid, time, and assisting in assigned tasks and other obvious activities on behalf of the individual (Langford, Bowsher & Moloney, 1997). Physical support also involves providing physical care and assistance with household tasks (Makabe & Hull, 2000). A study reported that instrumental support could have emotional meaning as well (Brown, Nesse, Vinokur & Smith, 2003), as it provides social interaction. However, physical support is distinguished from emotional support as it can provide social interaction activities, such

as preparing meals, giving medication or participating in physical activities (Makabe & Hull, 2000).

2.11 Summary

This chapter described the impact of a child's chronic illness on the child's development, the family (including family resources and parent functioning) and sibling relationships. It has been shown that children's chronic illness has a monumental impact not only on the family, siblings and parental relationships, but also on the psychological development of the sick children themselves, their parents and their relationships with their siblings. Culture and religion also influences the effects of the chronic illness on family relationships. The development of the health care system in Saudi Arabia and the support provided has been included; it is crucial to identify and reduce the potential negative effects of childhood illness on Saudi families, and to explore the support mechanisms required by families to assist them in becoming resilient. Where a child has a chronic illness, some families are more likely to experience higher demands and are at increased risk and experience vulnerability more than other families. Without adequate support, these families can experience significant stress. A critique of the literature relevant to resilience will be discussed and reviewed in the following chapter.

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Chapter 3 : Review of the Resilience Literature

3.1 Introduction

According to Martin-Breen and Anderies (2011), resilience is a complex and topical construct subject to ongoing debate in the current body of literature. These authors attribute this to the fact that the concept has been used in many fields of study, such as political science, business administration, sociology, ecology, psychology, and health (e.g., nursing). However, the shared use of this singular term does not mean that the meanings of resilience are cohesive or related across these fields, as there are various definitions and are used in different contexts (Martin-Breen & Anderies, 2011). As such, it is important to distinguish the meaning of resilience and its implications in research for this particular study.

With this in mind, the primary objective of this chapter is to define and explore the concept of resilience. The following section will outline the literature search strategy employed by the researcher in gathering and evaluating the studies used in this review. This chapter describes resilience as it applies to families with a child suffering from a chronic illness, considering perspectives from both Middle Eastern and non-Middle Eastern settings. The key factors influencing resilience will also be discussed. Finally, a summary of the entire literature review will be presented.

3.2 Literature Search Strategy

The strategy of reviewing pertinent literature on the study revolved around providing an overall context for the concepts the research sought to explain. The literature shed light on family resilience, as well as related topics like adversity, adaptation, and the proper functioning of family units. The review of the literature

needed to provide an insight into the factors that enhanced resilience in families with chronically ill children. The aim is to share a variety of related studies that provide different, enriching perspectives that may assist Saudi families to become resilient in these situations.

The researcher conducted a series of literature searches using electronic databases to gather relevant articles. These databases included CINAHL, PUBMED, SCOPUS, PROQUEST, and Nursing and Allied Health Science. The search included research studies conducted within the past 12 years (the articles selected are dated from 2002 to 2014). The search strategy used various combinations of terms, such as ‘family resilience’, ‘chronically ill children’, AND ‘Islamic countries’, OR ‘Western countries’ OR ‘Asia’ (see Table 3.1). From the body of research obtained, 18 empirical studies were identified and reviewed as related to family resilience with chronically ill children in global and Islamic contexts. Aside from the empirical research, 16 additional exploratory and descriptive research studies were used to help describe the topics discussed in this literature review.

Table 3.1

Literature Search Strategy Summary from 2002 to 2014

Database	Search Terms/Process					
	AND					Found to be relevant to the study
	family resilience	AND chronically ill children	Islamic countries	OR Western countries	OR Asia	
CINHAL	68	399	0	578	7	3
PUBMED	1,320	24	0	15	2	3
SCOPUS	2,440	61	0	56	8	0
PROQUEST (Nursing)	10,293	879	21	20	8	12

3.3 Family Resilience

According to Sorensen (2002), the concept of family resilience should be considered an inherent family trait that holds the family together in difficult times. Their overall outlook and approach to challenges serves as their foundation. Similarly, Monroe (2008) argued that resilience is a trait that is usually dormant within a family and only emerges in the event of a stressful situation, such as when a child is diagnosed with a chronic illness.

This section will further define and comprehensively explicate family resilience. It will be further divided into three sub-sections. The first will define the term ‘family resilience’ through a review of multiple studies, as well as how it relates to the family unit. The second will consist of a review of studies from different countries about family resilience in response to having a chronically ill child. This includes research from the USA, Canada, Australia, Belgium, the Netherlands, Russia, Korea, and China. The third sub-section will be a similar review, but this evaluation will focus on studies set in the context of the Middle East

and other Islamic countries, which includes Saudi Arabia, Qatar, Iran, Pakistan and Egypt.

3.3.1 Family resilience defined.

Resilience is the term used to describe the ability of a person to withstand or recover quickly from difficult conditions (Grafton, Gillespie & Henderson, 2010). A number of definitions of resilience refer only to the process of adaptation in the presence of hardship (Grafton et al., 2010; Luthar & Cicchetti, 2000; Luthar et al., 2000; Masten, 2001; Masten & Reed, 2002). However, there is general consensus in the literature that resilience is a dynamic process incorporating positive adaptation or outcomes despite the experience of severe adversity, risk or significant threats to development (Luthar & Cicchetti, 2000; Luthar, Cicchetti & Becker, 2000; Masten, 2001; Masten & Reed, 2002). Resilience is therefore a two-dimensional construct incorporating both the exposure to risk, as well as positive adaptation (Luthar, 2006; Masten & Reed, 2002). This definition of resilience will be the construct operationalised in this particular study, which will be discussed in Section 3.6 ('Operationalising Resilience'). Resilience does not only refer to the corresponding response of the individual in an adverse situation, but also considers the level of stress they are experiencing.

Risk or adversity can refer to a range of environmental stressors faced by individuals, such as the accumulation of taxing or traumatic life events. Positive adaptation (or positive outcomes) may range along a continuum, from the absence of psychopathology to various indices of social competence (such as academic achievement and social relations with peers) and other positive behavioural outcomes (such as absence of internalising and externalising problems) (Luthar, 2006; Masten & Reed, 2002). Predictors of resilience, or protective factors,

ameliorate the negative effects of risk, and these consequently influence positive outcomes, despite the risk. Protective factors may include a range of factors within the individual (such as self-concept), the family (such as a close, positive relationship with a parent), and the wider community (such as support from a teacher or other community member) (Luthar, 2006; Masten & Reed, 2002).

Alternatively, Berk (2000) provides a relatively simple definition of resilience as ‘the ability to adapt effectively in the face of adversity’ (p. 10). A frequently used definition is provided by Luthar et al. (2000), who also noted that ‘resilience is a dynamic process encompassing positive adaptation within the context of significant adversity’ (p. 543). These two dimensions of resilience (namely, risk and positive adaptation) and the predictors of resilience (protective factors) will be discussed in greater detail in succeeding sections of this literature review.

Further, according to some writers resilience is a dynamic event that includes exhibition of positive adaptation when facing serious adversity or stress in life (Luthar, 2006). This definition already implies two important prerequisites that are necessary for the development of any kind of resilience:

- Being exposed to a major risk, stressful scenario or severe adversity.
- Attainment of positive adaptation despite continuous attacks on normal functioning, as well as development factors (Luthar, 2006).

This particular definition of resilience also echoes the aforementioned definitions that explain the term as a combination of the two dimensions. However, definitions of resilience in a social science context lose the capability to manage and overcome risks or setbacks using the least amount of resources and time (Finan, Zaurtra & Wershba, 2011; Ganong & Coleman, 2002; Walker, Holling, Carpenter & Kinzig, 2004). Resilience also encompasses being able to properly handle levels of

continuous stressful change, conserving resources while being stressed, surviving adverse changes efficiently using adjustment and adaptation of functions to make such experiences a learning lesson, as well as changing old functioning for new without creating an imbalance. When family members show all these aforementioned traits as a response to adversity, they are said to have developed family resilience (Ganong & Coleman, 2002; Walker et al., 2004). It is important to note this definition of resilience, as this study seeks to explore family resilience in the context of Saudi Arabian family units. Although individual resilience is an important topic in this study, much of the focus will be on resilience in the family unit. Aside from the fact that this research will investigate Saudi Arabian families, resilience was also found to be learnt by individuals at an early age, starting with their families (Walsh, 2006).

In the past decade, research studies have been published on the nature of resilience as seen in family units who face adversity or cope with various stressful situations (Grafton et al., 2010). Patterson (2002) first examined the nature of resilience using the concept of final outcomes of resilience at a familial level. This criteria evaluated the competence of the family unit and therefore their resilience. This assessment of family resilience was discussed relative to the special functionality that family units have not only for the family members, but also at the social level (see Table 3.2). An example of this is when the family is able to adequately provide for the physical, psychological, social and spiritual development of children and adults (Patterson, 2002). This not only benefits the family unit itself, but also society, as the children are raised to become productive contributors to their community who are able to fulfill their roles and do no harm others.

Table 3.2

*Outcomes on A Familial Level Conceptualised Using the Family's Core Functions**(Patterson, 2002)*

FAMILY-LEVEL OUTCOMES CONCEPTUALISED IN TERMS OF THE FAMILY'S CORE FUNCTIONS			
Family Function	Ways Each Function Provides Benefits To		Examples of Positive and Negative Family-Level Outcomes
	Individual Family Members	Society	
Membership and family formation	<ul style="list-style-type: none"> • Provides a sense of belonging • Provides personal and social identity • Provides meaning and direction for life 	<ul style="list-style-type: none"> • Controls reproductive function • Assures continuation of the species 	<ul style="list-style-type: none"> + Commitment to and maintenance of family unit + Addition of children is planned and desired – Divorce
Economic support	<ul style="list-style-type: none"> • Provides for basic needs of food, shelter, and clothing, and other resources to enhance human development 	<ul style="list-style-type: none"> • Contributes to healthy development of members who contribute to society (and who need fewer public resources) 	<ul style="list-style-type: none"> + Adequate food and clothing + Safe housing – Child neglect – Homelessness
Nurturance, education, and socialisation	<ul style="list-style-type: none"> • Provides for the physical, psychological, social, and spiritual development of children and adults 	<ul style="list-style-type: none"> • Prepares and socialises children for productive adult roles • Supports adults in being productive members of society • Controls antisocial behaviour and protects society from harm 	<ul style="list-style-type: none"> + Family love and mutual support + Marital commitment and satisfaction + Securely attached children – Domestic violence – Child abuse
Protection of vulnerable members	<ul style="list-style-type: none"> • Provides protective care and support for young, ill, disabled, or otherwise vulnerable members 	<ul style="list-style-type: none"> • Minimises public responsibility for care of vulnerable, dependent individuals 	<ul style="list-style-type: none"> + Family care for child with special needs – Elder abuse

Table 3.2 above outlines the different functions of the family unit, and how these benefit the individuals belonging to the family, as well as the society they are part of. The final column contains examples of how these functions are fulfilled through positive effects, while negative effects present as consequences when functions are unfulfilled. This table explains how families exhibit varying levels of resilience through both positive and negative outcomes, with more resilient families displaying more positive traits and less resilient ones displaying negative traits. It points to which family functions are the source of adversity and their corresponding responses (Patterson, 2002).

Further, according to Monroe (2008), resilience can take different approaches and is 'multi-faceted'. This implies that every individual responds to stressful situations in a variety of ways (Monroe, 2008). Monroe also goes on to outline that the definitions of resilience available in the literature might not truly explain resilience, but they still provide insight on the various types of resilience and processes that lead to better and stronger outcomes, as observed in some situations. Monroe outlined that resilience is a measurement of elasticity, which reflects on the flexibility of a family towards the changes observed once a child is diagnosed with a chronic illness, and the degree or extent of challenges that the family can experience and still maintain composure. The elasticity aspect also refers to the ability of the family to regain its original position after the stretching force is removed (Monroe, 2008).

Another definition analysed by Monroe (2008), which was originally provided by Walsh (2006), outlines that resilience refers to the ability of the family to move forward after a prolonged period of stress. The definition seems to build on the definition provided by McCubbin and Huang (1989). The essence of McCubbin

and Huang's definition is that resilience refers to regaining the original position, while Walsh's (2006) definition implies that one should not just go back but assume an even better position. Therefore, the essence of Walsh's definition is that one should not just resist dysfunctional behaviours, but should also emerge with improved actions. Family resilience can thus be proactively viewed as an opportunity for the development of family members in the face of adversity, instead of just dwelling on the problems.

When a family unit faces a stressful situation, such as having a child who is chronically ill, its members collectively experience emotional, cognitive and instrumental instability, which disrupts normal family functions (Grafton et al., 2010; McAllister & McKinnon, 2009). During these times, the family needs to be able to find hidden strengths and divert resources to adjust and handle such situations correctly (Grafton et al., 2010; McAllister & McKinnon, 2009). Numerous research studies, which evaluate the responses of family units to chronic illness of a family member, consider resilience as being essential for adjustment (Black & Lobo, 2008; Grafton et al., 2010; McAllister & McKinnon, 2009; Taylor & Wang, 2012;).

In a family unit, whenever a child is diagnosed with any chronic illness, the entire family, especially the parents, face extra burdens and excessive amounts of stress (Lee, Harrington, Louie & Newschaffer, 2008). This type of stress brings about sudden and forced alterations in the family unit, particularly in areas such as the functions of different family members. Aside from these, the connectivity between these functions, lifestyle and priorities based on family values are also affected (Lee et al., 2008).

3.3.2 Family resilience studies globally.

Over the last few decades, most of the research and published literature on the construct of resilience has explored positive adaptation, especially in children and family units, in the face of adversity. Resilience research theory has been advanced in developing the concepts of risk and function, as well as prospective processes in a family unit that affect the degree of positive end outcomes. However, a major issue that resilience researchers in other parts of the world face is that current resilience theory is based on Western culture (Haimour & Abu-Hawwash, 2012). This issue also applies to the concept of individuals, family units and relationship factors.

However, many studies on family resilience have been conducted in both Western and non-Western countries. These countries include the USA (Bellin, Kovacs & Sawin, 2008; Gerhardt et al., 2003; Kilmer, Cook, Taylor, Kane & Clark, 2008; Seltzer, Greenberg, Floyd, Pettee & Hong, 2011), Canada (Cloutier, Manion, Walker & Johnson, 2002), Australia (Hamall, Heard, Inder, McGill & Kay-Lambkin, 2014; Rayner & Moore, 2007), Belgium (Greeff, Vansteenwegen & Ide, 2006), the Netherlands (Knestrict & Kuchey, 2009), Russia (Zashikhina & Hagglof, 2009), Korea (Lee et al., 2004) and China (Liu, Lambert & Lambert, 2007). These studies sought to identify and explore the factors that could contribute to family resilience around the world. They demonstrated strong similarities in their results, regardless of where they were conducted.

3.3.2.1 American and North American Studies.

Studies conducted in the USA (Bellin et al., 2008; Gerhardt et al., 2003; Kilmer et al., 2008; Seltzer et al., 2011) were the most numerous, and also had the most variety. The research selected for this literature review varied in terms of the

research type, methodological design and type of respondents. These studies observed very diverse key influences for family resilience, including: emotional support from family and friends (Bellin et al., 2008; Gerhardt et al., 2003), positive family relationships and/or home environment (Bellin et al., 2008; Kilmer et al., 2008), participation in social support groups (Seltzer et al., 2011), type and/or severity of the child's illness (Gerhardt et al., 2003; Kilmer et al., 2008; Seltzer et al., 2011), poverty (Kilmer et al., 2008; Seltzer et al., 2011) and spirituality (Bellin et al., 2008).

Additionally, the mixed-methods longitudinal study of Seltzer et al. (2011) sought to investigate how the child's disability (of 218 parents who participated in the Wisconsin Longitudinal Study (WLS)) affected the various aspects of their lives. The WLS began in 1957, with a random sample of young men and women who graduated from Wisconsin high schools that same year, with data-gathering taking place in 1975 and 1992. The 218 parents who had children with disabilities were isolated to serve as the respondents to this study, along with a normative comparison group. This comparison group comprised of 218 parents of typically growing children, who came from the same graduating years and also participated in the WLS. The disabilities of the experimental respondents' children were further divided into those that had developmental disabilities ($N = 165$) and those that had serious mental health problems ($N = 53$). Factors relating to family background, educational and occupational characteristics, participation in social organisations, as well as physical and psychological well being were measured in this study, and how it related to their resilience. The results found that the sample group whose children suffered from developmental disabilities were observed to have lower rates of employment, a larger family size, and lower levels of social participation. However,

they did not vary in terms of educational status, marital status, or physical and psychological well being when contrasted to the comparison group. The parents of children with mental health disorders were more likely to suffer from health conditions, depression and alcoholism. However, their educational, marital and occupational status did not vary with the comparison group.

Moreover, Gerhardt et al. (2003) employed a comparative quantitative research design to investigate parental distress, family functioning, and the role of social support among 64 parents (64 mothers and 46 fathers) of children suffering from juvenile rheumatoid arthritis (JRA) in the USA. Four measures were used in the research (Gerhardt et al., 2003). The first was a demographic questionnaire. The second was 'Symptoms Checklist 90-Revised' (or SCL-90-R), a self-report inventory of psychological symptoms to assess parental distress. The third was a family environment scale (FES), which measured the family's social climate or family functioning. A fourth was the 'Norbeck Social Support Interview', where respondents enumerated significant people in their lives and subsequently answered six structured questions that measured their satisfaction with each person mentioned. As for the findings, Gerhardt et al. (2003) observed that families of children suffering from JRA did not vary from the comparison group (64 families with healthy children) in terms of their parental distress, family functioning and social support. However, the respondent mothers of chronically ill children had significantly higher SCL-90-R scores. The researchers speculated that the lack of significant variations between the two sample groups was because JRA is not a severe chronic illness, compared to other conditions such as physical illnesses or developmental disorders. However, the level of support from the spouse and family members was also observed to have a significant effect on resilience levels. These

positive attitudes and relationships mitigated the stress, anxiety and exhaustion felt by the parents as they cared for their children suffering from JRA.

In addition, the mixed-methods study of Bellin et al. (2008) investigated the lived experiences of 155 brothers and sisters (aged 11 to 18) of children suffering from spina bifida (SB), specifically with regards to how they coped with this situation. The quantitative aspect of Bellin et al.'s (2008) study focused on observing the effects of 'individual (attitude towards illness), family (family satisfaction, sibling warmth and comfort), and environmental factors (peer support)' (p. 201), to the resilience of these siblings through a self-administered questionnaire. In contrast, the qualitative component investigated the daily experiences of the respondents through open-ended questions. The results of the study indicated several factors were significantly related to developing resilience. These included spirituality, cohesive family ties and supportive peer friendships. Spirituality was observed as a factor that contributed greatly to the respondents having a proper perspective regarding the condition of their ill sibling. Their faith helped them find meaning in their adverse situation and understand what they were going through, which mitigated the anxiety or uncertainty they felt. As for cohesive family ties, the relationships with other family members assisted in developing resilient attitudes among these children. Parents, grandparents and even other siblings helped these respondents cope, through answering their questions about their siblings' condition, providing comfort and maintaining the harmony in the family. The respondents' friendships also helped them develop resilient behaviours. Aside from the emotional support they received from their friends, these relationships also allowed them the opportunity to temporarily forget about their problems and distress (through leisure activities).

Similar to the previous study, Kilmer et al. (2008) investigated 56 siblings of children suffering from severe emotional disturbances (SED). These children experienced the same risks as their diagnosed siblings, and both sets of children were compared to each other in the study. Their exposure to risk, resources, and level of resilience were studied through several measures. These included the 'Behavioural and Emotional Rating Scale' (which measured interpersonal strength, family involvement, intrapersonal strength, and affective strength), the 'Parent-Child Rating Scale' (which measured negative peer social skills, positive peer social skills, assertive social skills, task orientation, shy-anxious/withdrawn, and frustration tolerance) and the 'Life Events Checklist'. These inventories were undertaken by their caregivers (parent or legal guardian). The findings observed that much like their diagnosed siblings, the respondents had been exposed to extremely high levels of adversity. The level of resilience was also found to have been significantly correlated to the level of stress they experienced, as well as the level of their relationships with their ill sibling and their family. Firstly, the higher the overall stress levels the siblings experienced, the lower their level of resilience. The siblings were also observed to be more well adjusted if the level of family functioning was higher, which was attributed to the harmonious relationships mitigating the adverse effects of stress and anxiety. The severity of the ill sibling's condition was also correlated to their siblings' level of resilience (ones who were not ill). In addition to these three causes, the family's socioeconomic status also had a significant effect on the level of sibling resilience. The less financially stable the family was, the more anxiety and hopelessness the siblings felt, which was attributed to the financial burden of the condition of their ill sibling.

A Canadian study by Cloutier et al. (2002) found similar key influences on family resilience. The first was emotional support from family members, particularly one's spouse. The other was having a healthy family relationship. These findings were very similar to the findings of Bellin et al. (2008), Gerhardt et al. (2003) and Kilmer et al. (2008). Cloutier et al. (2002) made use of a quantitative longitudinal study to investigate resilience among 32 couples with chronically ill children, who underwent emotionally focused couple therapy (EFT) in Canada. The factor related to resilience observed in this study was the couples' levels of marital distress (as a result of coping with a chronically ill child), which was measured by the 'Dyadic Adjustment Scale' (DAS) and the 'Miller Social Intimacy Scale' (MSIS). These were measured immediately after treatment, and two years following said treatment. The results found that 76.9 per cent of couples that underwent EFT were able to decrease their levels of marital distress, and 61.5 per cent were able to maintain this in the second year. Aside from the observed long term effects of EFT, the research also revealed that couples who underwent EFT had higher success rates in overcoming marital distress compared to the control group. The key features of EFT that helped with resilience included open communication among spouses, the knowledge of how or when to provide support to one's spouse, as well as having an opportunity to do leisurely activities as a couple, to bond and release stress.

3.3.2.2 Europe.

The review was able to amass three studies from Europe, specifically from Belgium (Greeff et al., 2006), the Netherlands (Knestrict & Kuchey, 2009) and Russia (Zashikhina & Hagglof, 2009). The common factors affecting family resilience included solidarity among family members (Greeff et al., 2006; Knestrict & Kuchey, 2009) and socioeconomic status (Knestrict & Kuchey, 2009; Zashikhina

& Hagglof, 2009). Other key influences observed in both Europe (and the aforementioned North American studies) were social support (Bellin et al., 2008; Cloutier, et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Seltzer et al., 2011), maintaining a positive perspective on the ill child's condition (Bellin et al., 2008; Knestrict & Kuchey, 2009) and the severity of the disease (Gerhardt et al., 2003; Kilmer, et al., 2008; Seltzer et al., 2011; Zashikhina & Hagglof, 2009).

The cross-sectional, correlational and exploratory study of Greeff et al. (2006) investigated resilience in 30 Belgian families with a member suffering from a psychological disorder. The researchers made use of six instruments to measure various constructs: the 'Family Crisis Oriented Personal Evaluation Scale' (FCOPES) for coping strategies, the 'Social Support Index' (SSI) for the level by which they depend on their community, the 'Family Hardiness Index' (FHI) for strength or control over life problems, the 'Relatives and Friend Support Index' (RFS) for the level by which they depend on drawing support from these people as a matter of coping, the 'Family Sense of Coherence Scale' (FSC) for the level by which members believe that their environment is predictable or structured, and a biographical questionnaire for demographic data. The results showed that family hardiness was a very significant factor for family coherence or resilience among parents, as well as their children (siblings of the chronically ill child). Family hardiness denoted that members of the family were united and used their strengths (whether individually or collectively) to address their stressors. For parents, aside from family hardiness, the use of passive coping strategies or avoiding the problem was commonly employed as an adaptation tool. For the children, social support from their community was also related to their perspective of family resilience.

Further, Knestrict and Kuchey's (2009) qualitative descriptive study investigated resilience of families in the Netherlands as they raised a child with severe disabilities. The research studied 20 pairs of parents, who underwent interviews (as pairs), focus group interviews and home observations. The results found that the family's socioeconomic status had a significant effect on their resilience, as the financial burden of caring for children with special needs was a great stressor, especially to those who were not as economically stable. The ability for the parents and the rest of the family to reflect on their situation, as a way to readjust their perspective was also observed as vital to developing resilience strategies. When faced with difficult situations that they did not often comprehend at the onset, reflection allowed families to make sense of their child, their disability, and what it meant to be a family. Another factor that contributed to the development of resilience strategies was establishing a family rhythm or a set of 'consistent rules, rituals, and routines' (Knestrict & Kuchey, 2009, p. 227). The researchers observed that coping strategies were much more easily integrated when they were related to or were part of existing regular activities (e.g., the opportunity to reflect could be developed during times when families would gather for meals or leisure time).

In addition, the study undertaken by Zashikhina and Hagglof (2009) focused on the factors that affected family functioning among Northern Russian families with a child suffering from a chronic physical illness. They specifically sought to investigate three issues: if these families were more susceptible to problematic family functioning compared to a control group with healthy children; if disease severity was associated with family functioning, and if family functioning differed among three disease groups (diabetes, asthma and epilepsy). The 148 families serving as experimental respondents (as well as the 301 control group) had their

children's medical records obtained, had their socioeconomic status evaluated (based on parent occupation and level of education as well as family income) and were asked to complete a self-report inventory about their family functioning. The results revealed that the level of functioning did not differ between the experimental and control group. However, there were a number of factors that significantly predicted family functioning. The more severe the condition of the child, the more problematic the family was in terms of their functioning. The longer a child suffered from the illness also led to greater dysfunction. In addition, households with a lower socioeconomic status, as well as those with a single parent, also predicted problematic family functioning.

3.3.2.3 Australia.

From Australia, two studies were identified (Hamall et al., 2014; Rayner & Moore, 2007). One of the common factors affecting family resilience observed in these two studies was parental well being or their parenting style. Another significant contributor to family resilience isolated in these two studies was parental stress. These observations were quite similar to the study of Cloutier et al. (2002), attributing parents' emotional stress to lower levels of family resilience. Bellin et al. (2008) and Kilmer et al. (2008) attributed positive family relationships and/or home environment as predictors of resilience.

Additionally, the quantitative descriptive research of Rayner and Moore (2007) sought to study how stress and resilience manifested in families of chronically ill children in Australia. Another objective was to observe how parenting stress, parenting style, family resources (annual income, educational levels, number of children) and illness characteristics (behaviour of ill child, required care time for ill child) were interrelated. The study employed 77 parents (69 mothers and eight

fathers) and 77 children (37 boys and 40 girls) with a chronic illness or disability. The parent respondents completed the following inventories: 'Parenting Daily Hassles Scale' (measuring parental stress), 'Child Behaviour Checklist' (measuring the behaviour of both their ill and well children), family resources (self-reported and measuring annual income, the mother's educational level, and number of children), and illness severity (self-reported). The well children, in contrast, accomplished the 'Parenting Styles Questionnaire', primarily relating to their perception of their parents' degree of warmth and responsiveness, as well as their ability to give their children independence. The results of the study indicated that parents of chronically ill children were more significantly stressed, when compared by the researchers to the norm (based on previous similar studies they reviewed). High parental stress was associated with the difficult behaviour of their ill children, and the high demands for caring for them. Significant levels of parental stress were also observed in parents whose children identified them as having high behavioural control.

Moreover, the mixed-methods experimental study of Hamall et al. (2014) investigated the effects of families undergoing the 'Child Illness and Resilience Program' (CHiRP), as a way to improve their resilience and well being. CHiRP is an intervention programme that aims to 'assist families to identify existing strengths and provide strategies that target key protective factors and processes that enhance family resilience, such as family functioning, coping skills, and utilising resources including social support' (Hamall et al., 2014, p. 3). The sample group comprised of 353 parents of children suffering from a chronic illness at a paediatric hospital in regional New South Wales. The CHiRP is comprised of three steps (see Figure 3.1). The first is a routine dissemination, in which parents (who have a child discharged from the hospital) receive a 'Family Resilience and Wellbeing Factsheet' containing

psych-education and practical family resilience-building strategies. This step also ensures that all families, regardless of the reason for admission, will be provided with standardised family resilience and well being support information. The second step was a targeted dissemination, in which parents with a child who regularly attends one of the four outpatient clinics in the experimental hospital are asked to participate in a booklet intervention. This booklet, entitled 'Strong Parents, Resilient Families', focuses on the parents and their strengths, while employing a cognitive behavioural approach to foster family resilience. Some of the contents of the booklet include resilience-building activities, family goal setting, and family strengths identification. These parents also completed (in the second step) the 'Parent Outpatient Survey' (POS) three months after receiving the booklet. The third step involves those who report parental distress in the POS from the second step. These parents were invited to join an information support group, an education, support and skills development programme run by two trained facilitators. This programme was based on the booklet from the second step, but with the added benefit of having parents share their experiences and best practices. The ISG ran for six weeks; the first week was an introductory session where participants met in person. During weeks two to five, the content and activities were posted in an online forum moderated by the facilitator. The participating parents then conducted the resilience-building activities with their families, and posted their experiences in the forum, much like the first session. The final session was another face-to-face meeting with all participants, in which they discussed their experiences and their overall participation in the ISG. The researchers hypothesised that families participating in the CHiRP intervention would experience positive outcomes in terms of mental health and overall family resilience. This is due to the comprehensive, consistent

and relatively lengthy period in which they attempted to build resilience in their families. Among the key focus points of the programme were parental well being, family functioning, family beliefs and social support. These were isolated as the most important factors that contributed to overall family resilience (see Figure 3.1).

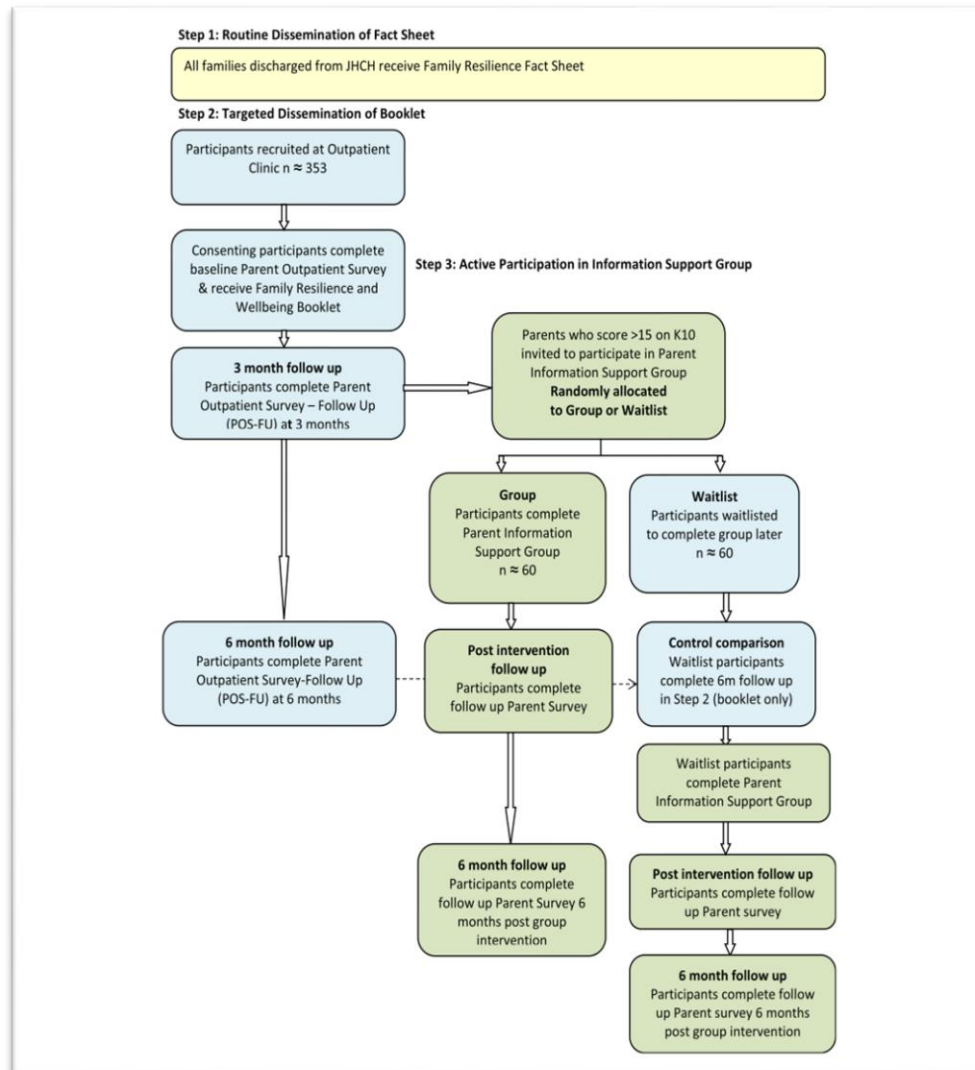


Figure 3.1: Flow diagram of the CHiRP research design (Hamall et al., 2014).

3.3.2.4 Asia.

Two studies were reviewed from Asia, more specifically from East Asia. One study was from Korea (Lee et al., 2004), while the other was from China (Liu et al., 2007). The common factor between these two studies, which they also shared with the other studies in this review, was the emphasis on social support from family and friends. This was particularly evident based on the fact that family functioning was observed as a major priority for respondents in both studies (Lee et al., 2004; Liu et al., 2007). Lee et al. (2004) further stated that the focus on the family unit was a result of Korea (as well as many Asian cultures) being a collectivist society.

Firstly, Lee et al. (2004) employed a mixed-methods design that investigated resilience among 11 Korean families with a chronically ill child. The study also aimed to explore the relationship between family resilience and how the family functioned. The design of the research consisted of three parts. The first phase was a comprehensive literature review that addressed family resilience, to provide conceptual definitions and contexts to be used in the analysis. The second step was fieldwork, where in-depth interviews were conducted on the mothers and fathers, as well as their children. The interview investigated the actions, coping, adaptation, and resources employed by families in dealing with a chronically ill child. The third and final phase was the analytical phase, where results from the first two steps were integrated. Recurring themes were determined to come up with the findings for the study. The results determined that resilience was defined by a positive change in a family's functioning, in accordance with their value system, when they faced an adverse situation. The research also found that there were many ways resilience could be displayed by families, which they categorised into four dimensions. These were: intrinsic family member characteristics (cohesion, maturity, positivity and

faith), family member orientation related to family characteristics (connectedness, open communication and balancing the needs of each member), responsiveness to stress (adaptability, patience, and control of stress), and external orientation (resourcefulness and harmonious relationship with health care staff). The researchers concluded that the family outcomes, or how the family displayed their level of resilience, largely depended on how they functioned as a family.

Further, Liu et al.'s (2007) study investigated how Chinese parents coped and attempted to maintain a functional family life despite their child's mental illness. The descriptive correlational study surveyed 97 Chinese parents on caregiver burden, resilience patterns, and their demographic characteristics (which included educational level, working status, educational level of their child, diagnosis of the child and family economic status) using the 'Caregiver Burden Scale', the 'Coping Health Inventory for Parents', and the 'Social Demographics Questionnaire'. Further, the interrelationships between these three factors were explored. The findings of the study showed that the respondents experienced significant caregiver burden as a result of caring for their mentally ill child. These were caused by feelings of pressure and anxiety (connected to having to care for their child, often while making a living), as well as a decrease in their leisure time. The physical health of the parents and the educational level of their children were significant predictors of caregiver burden. There was also a negative correlation observed between the level of caregiver burden and the level of resilience. As such, a significant number of the respondents reported that they used a relatively limited number of coping patterns to maintain a functional family life. The parent's physical health and their educational levels were found to be significant predictors of resilience. In addition, it is worth noting that despite the limited ways of coping employed by the respondents, among

the most commonly recurring was reliance on family members, relatives, neighbours and close friends. The caregiver-parents noted that they commonly relied on emotional support from their spouse or their other children as a way to assuage their exhaustion, stress and anxiety. They also explained that sharing their experiences with their neighbours and friends not only helped these people understand their difficult situation, but it was also a way for them to release their frustrations.

3.3.2.5 Summary table of family resilience studies globally.

Table 3.3 summarises all the above studies of resilience in families from multiple countries in America and Northern America, Europe, Asia and Australia. The studies investigated various contexts, and employed a range of methods, samples, aims and data analysis techniques.

Table 3.3

Summary of Family Resilience Studies Globally

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
Bellin et al. (2008): Risk and protective influences in the lives of siblings of youths with spina bifida.	Mixed-methods study	155 brothers and sisters of children suffering from spina bifida	Content analysis	Several factors are significantly related to developing resilience, which included spirituality, cohesive family ties, and supportive peer friendships.
Cloutier et al. (2002): Emotionally focused interventions for couples with chronically ill children: a 2-year follow up.	Quantitative longitudinal study	32 couples with chronically ill children who underwent emotionally focused couple therapy (EFT) in Canada	Descriptive analysis and one-way analysis of variance	76.9 per cent of the couples with chronically ill children who underwent EFT were found to have been resilient in terms of their marital relationship post-treatment. 61.5 per cent were able to maintain

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
				these improvements or recoveries two years after.
Gerhardt et al. (2003): Comparing parental distress, family functioning, and the role of social support for caregivers with and without a child with JRA.	Comparative quantitative design.	64 parents (64 mothers and 46 fathers) of children suffering from JRA in the USA.	Two tailed, independent t-tests; chi-square analysis; hierarchical multiple regression.	Parents of children suffering from JRA were no different from the comparison group in terms of their parental distress, family functioning, and social support, but mothers were shown to have significantly higher SCL-90-R scores. The level of family support was also observed to have a significant effect on resilience levels.
Greeff et al. (2006): Resiliency in families with a member with a psychological disorder.	Cross-sectional, correlational, and exploratory study.	30 Belgian families with a member suffering from a psychological disorder.	Analysis of variance.	Family hardiness was a very significant factor for family coherence or resilience among parents and siblings of the chronically ill child. For parents, the use of passive coping strategies or

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
				avoiding the problem were also resilience strategies; while the children sought social support from their community.
Hamall et al. (2014): The Child Illness and Resilience Program (CHiRP): a study protocol of a stepped care intervention to improve the resilience and wellbeing of families living with childhood chronic illness.	Mixed-methods experimental study.	353 parents of children suffering from chronic illness in Australia.	Descriptive analysis; One-way analysis of variance; analysis of covariance.	The researchers hypothesised that families participating in the CHiRP intervention shall experience positive outcomes in terms of mental health and overall family resilience.
Kilmer et al. (2008): Siblings of children with severe emotional disturbances: risks, resources, and adaptation.	Descriptive quantitative study.	56 siblings of children suffering from SED.	Univariate analysis of variance; Multivariate analysis of variance.	Much like their diagnosed siblings, the respondents had been exposed to extremely high levels of adversity. The level of resilience was correlated to the level of stress experienced, family relationships, the severity of their sibling's

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
				condition, and their socioeconomic status.
Knestricht & Kuchey (2009): Welcome to Holland: characteristics of resilient families raising children with severe disabilities.	Descriptive qualitative study.	20 pairs of parents of a child with severe disabilities in the Netherlands.	Descriptive analysis.	The family's socioeconomic status, ability to reflect on their situation, and the establishment of family rhythm had a significant effect on their resilience.
Lee et al. (2004): Concept development of family resilience: A study of Korean families with a chronically ill child.	Mixed-methods study.	11 parents of chronically ill children in South Korea.	Retroduction analysis (combination of inductive and deductive methods); qualitative analysis; thematic analytic technique.	Family resilience was observed as a way for them to change their way of functioning in order to solve their adversities. Four kinds of categories of how family resilience is displayed were determined: intrinsic family characteristics, family member orientation related to family characteristics, responsiveness to stress, and external orientation.

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
Liu et al. (2007): Caregiver burden and coping patterns of Chinese parents of a child with a mental illness.	Descriptive correlational study.	97 Chinese parents of children with mental illnesses.	Student <i>t</i> -test; one-way analysis of variance; correlation; multiple regressions.	The respondents experienced significant caregiver burden as a result of caring for their mentally ill child, which were caused by feelings of pressure and anxiety, as well as a decrease in their leisure time.
Rayner & Moore (2007): Stress and ameliorating factors among families with a seriously ill or disabled child.	Quantitative descriptive study.	77 parents and well siblings of chronically ill children in Australia.	Multivariate analysis of variance.	Parents of chronically ill children had significant levels of stress, due to the difficulties that come with their ill child's behaviour and the high demands of caring for them.
Seltzer et al. (2011): Life course impacts of parenting a child with a disability.	Mixed-methods longitudinal study.	218 parents of children with disabilities who in Wisconsin.	Descriptive analysis and analysis of covariance.	Parents of children having developmental disabilities were found to have lower employment rates, bigger family sizes, and lower social participation. Parents of children with mental health disorders were more likely to suffer

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
				from physical conditions, depression, and alcoholism.
Zashikhina & Hagglof (2009): Family functioning and juvenile chronic physical illness in Northern Russia.	Qualitative cross-sectional study.	148 Russian adolescents with chronic physical illnesses and their mothers.	Statistical Package for the Social Sciences (SPSS).	The level of functioning did not differ between the experimental and control group. The severity and length of the condition of the child as well as their socioeconomic status predicted family resilience.

3.3.3 Family resilience studies in the Middle East and other Islamic countries.

Regarding resilience in the Saudi Arabian context, there is currently a paucity of substantial literature available to conduct cross-cultural validation of the theory and concept of resilience in such a setting (Haimour & Abu-Hawwash, 2012). A thorough search of the literature emphasised the paucity of research studies that focus on the concept of resilience in Saudi Arabia. To compensate for this, the search was expanded to other countries with similar cultures as Saudi Arabia, in terms of religion and geographic location (Qatar, Pakistan, Egypt and Iran).

Resilience is a concept combining the unique traits of all individuals and family units, both social and communal, as well as the political environment. Many studies, including those of Luthar and Cicchetti (2000) and Seccombe (2002), as well as Luthar et al. (2000) have already indicated that the development of resilience is associated with the vulnerable and family protective factors in a person's environment. It is important to understand that in many Middle Eastern and other Islamic countries, family units and communities (as well as individuals) exist in a collectivist system (McCabe, Feghali & Abdallah, 2008). According to studies by McCabe et al., as well as Pellegrini and Scandura (2008), families in these cultures follow the patriarchal system for communal living, where traditional gender roles are fixed. In many cultures (such as the Middle East), women and children are not encouraged to think independently as they are in the West (Pellegrini & Scandura, 2008). Much of the independent thinking and decision making is reserved for adult males (such as fathers or grandfathers), who are usually the head of families (Pellegrini & Scandura, 2008).

Many authors, such as Seccombe (2002) and Ungar (2004), expressed the view that the development of resilience depends not only on the individual's disposition but also on other factors, such as family protectiveness and cultural practices or community phenomenon. This is especially true in Saudi Arabia and the Middle East, which are predominantly Islamic countries (McCabe et al., 2008). The general conservativeness of the religion and its pronounced impact on these societies has shaped their general culture, as well as the individuals in those societies (McCabe et al., 2008). Seccombe (2002) also stated that to understand resilience in the context of non-Western societies, researchers must pay attention to the structural differences in these societies. In addition, Gilligan (2004) stated that in children and youth, resilience is better defined as 'a variable quality that results from a process of continuous interactions between a person and favourable factors in the surrounding context in any individual's life' (p. 93). Therefore, the level of resilience attained by any person or family within their own cultural context is directly associated to the quality of resources and elements available in that context for supporting resilience (Gilligan, 2004).

3.3.3.1 Factors affecting family resilience in the Middle East and other Islamic countries.

This section will detail empirical research that discusses resilience in the context of families having a chronically ill child in the Middle East and other Islamic countries. Six studies were identified and were further divided into sub-sections, based on their common themes regarding their connection to family resilience. These were related to factors that affected family resilience (Aldosari & Pufpaff, 2014; Haimour & Abu-Hawwash, 2012; Motamedi, Seyednour, Noorikhajavi & Afgah,

2007) and strategies for coping that improved family resilience (Kheir et al., 2012; Lakhani, Gavino & Yousafzai, 2013; Mohammed, Mohammed & Hussien, 2013).

Based on the literature reviewed, among the major factors affecting family resilience in the Middle East and other Islamic countries is the type of chronic illness the child suffered from. This was the aim of a qualitative cross-sectional research by Motamedi et al. (2007). Their study investigated the level of depression among the mothers of disabled children in Iran and their overall level of resilience. The mothers were placed into three experimental groups for comparison, according to the severity of their child's condition: intellectual disability with ability to learn, intellectual disability that can be trained, as well as brain damage and other cases. The research findings indicated that out of all respondents (comprising all three sub-groups), 73 per cent of the mothers suffered from depression, and 21 per cent experienced severe depression. Further, there was a significant relationship between the mother's depression and their ability to cope with adversity, with their child's disability type. It was particularly noted that in cases of the child having brain damage, 14 of the respondent mothers suffered from severe depression, while 25 had a mild case. Both of these numbers were significantly higher compared to their counterparts (intellectual disability with ability to learn and intellectual disability that can be trained). This led to the conclusion that the type of chronic illness (which was brain injury, in this case) had a significant association with depression, and consequently the mothers' resilience.

Related to the type of illness, its severity was also found to be a significant factor in affecting family resilience. The descriptive quantitative study of Haimour and Abu-Hawwash (2012) investigated how the overall quality of life of Saudi families with a child suffering from a disability, using the Arabic version of the

WHO 'Quality of Life' (WHOQOL) measurement. This survey measured how the families (through the responses of both mothers and fathers) perceived their position in life 'in the context of the culture and value systems in which they live in, and in relation to their goals, expectations, standards, and concerns' (WHOQOL, p. 39), as well as how effectively they functioned as a family unit. The sample included 306 families, who were further divided into four experimental groups, depending on the condition of their child (e.g., intellectual disability, learning disability, physical disability and autism). The results showed that the quality of life (QOL) scores varied according to the type of condition the child suffered from. Families of children with learning disabilities had the highest QOL scores, followed by those who suffered from physical disabilities, than those with an intellectual disability. Families of children with autism garnered the lowest QOL scores (with most having negative). Those who had comparably higher QOL scores frequently experienced anxiety as a result of having to care for their disabled children, or worrying about how they would function without their parents. The financial difficulty associated with the necessities for caring for their children (e.g., check-ups and therapy sessions) also contributed to low QOL. In addition to the type of disability, its severity (both between experimental groups and between different families within each group) also had a significant effect on the level of resilience in these families.

Similar to the previous two studies, Aldosari and Pufpaff (2014) also found that the severity of the child's condition (exhibited through their symptoms and actions) affected the parents' stress, and in turn, their resilience. However, they also found that the parents' perception of their parenting abilities caused the same effects. This descriptive comparative research investigated 17 pairs of Saudi parents with the use of the Arabic version of the 'Parent Stress Index' (PSI) to measure the relative

magnitude of stress in the parent-child relationship. This was divided into the child domain and the parent domain. The former (which rates how parents perceive how their child functions) includes sub-scales, such as distractability/hyperactivity, adaptability, reinforces parent, demandingness, mood, and acceptability. The parent domain pertains to how the parent perceives they are functioning and includes the following sub-scales: competence, isolation, attachment, health, role restriction, depression and spouse. A high score in a particular domain indicates that the source of stress or dysfunction is either the child or the parent himself/herself. The results of the study indicated that the mothers had significantly higher stress levels compared to their husbands in both child and parent domains, as well as the overall parent-child relationship. Regarding the child's characteristics, their demanding nature, lack of adaptability, lack of acceptability, and their tendency to be easily distracted and hyperactive were the major stressors for mothers. In terms of their own characteristics, their depression, the fact that their own life outside their family is restricted, and their perceived lack of competence produced the greatest stress levels among mothers compared to fathers.

3.3.3.2 Coping strategies for improving family resilience.

With regards to what helps improve family resilience, a study by Mohammed et al. (2013) found that information and knowledge about the condition of the chronically ill child was very helpful. The researchers made use of a descriptive comparative research study to observe 200 mothers (100 from Egypt and 100 from Saudi Arabia). These mothers had at least one child with a congenital anomaly. The research sought to investigate the differences in attitudes of both sets of mothers and how knowledgeable they were about the various aspects of their children's condition. The researchers observed no significant differences between both groups in terms of

attitudes and knowledge. With regards to attitude, both sets of mothers expressed negative views regarding the congenital anomalies in their children. Many of the respondents discussed feelings of anxiety, stress, fear, sadness and anger they regularly had as they dealt with the difficulties of having a chronically ill child (e.g., financial burdens, realising their child may not live a normal life, and fear of judgment from others). Two ways the respondents coped with their adversity however was through their faith in God and having an adequate amount of knowledge regarding their child's congenital anomaly. The latter helped them and their families become resilient in two ways. Firstly, the fact that they knew more about the condition allowed them to take care of their child more effectively, assuaging their worries about their child's comfort and overall well being. Secondly, the knowledge about how congenital anomaly develops in children as a result of the parents' reproductive health and overall wellness helps in seeking proper health care for them and the rest of their family. The information they obtained was also of great help for many respondents, who had or were considering having more children thereafter.

Additionally, Kheir et al. (2012) found that social and emotional support (from other people and even group programmes) helped strengthen resilience in families as they investigated the QOL of mothers who acted as their children's caregivers in Qatar. The descriptive quantitative study employed 98 mothers who were split into two groups. Fifty-six were caregivers of a child with autism, while 42 had a typically growing child. Based on the study's findings, mother-caregivers of children with autism rated their health as poor, and most of them further stated that it was likely to get worse. This was due to the stress that they felt from being the primary caregiver of their autistic child, leaving them with not much opportunity to

focus on their own health and wellness. However, in terms of their overall well being, the researchers found no significant differences between the QOL of the autism and non-autism groups. This was attributed to the fact that a large number of mothers from the autism group received emotional support from at least one source (spouse, family, friends and support groups, among others). Moreover, a significant portion of those who did not belong to any support group said that they would like to join one, if it were available. The emotional support was said to help the mothers in three ways. Firstly, the presence of other individuals allowed them to temporarily forget about their problems, providing a certain amount of relief (most commonly through prayer). Secondly, the support they received often helped with understanding the many uncertainties they had about their child's condition (e.g., how they would manage on their own in the future), thereby reducing their worries and anxieties. A third benefit was that the people who supported them (most especially other family members) also helped them with the responsibilities as their child's caregiver.

Related to the findings in the previous study, Lakhani et al. (2013) also found that family support (especially having an optimistic perspective), helped foster resilience among the Pakistani family unit. The researchers sought to observe the impact of caring for children with intellectual disability on the overall condition of their families, as perceived by their mothers (assessing positive contributions, social comparison with other families, understanding of disability, and perception of control). This descriptive quantitative study surveyed 54 Pakistani mothers with the use of the 'Kansas Inventory of Parental Perceptions' (KIPP). The KIPP consists of 98 items divided into four sub-scales: positive contribution, social comparison, causal attributions and mastery control. The findings indicated the mothers perceived

that caring for a child with an intellectual disability had a positive effect on family functioning and life. The reasons they gave included that family members were able to understand their life's purpose and learn through their special life experiences. Mothers also expressed that family members felt happiness and fulfillment as a result of caring for their child with an intellectual disability, and it also helped keep the family closely and strongly bonded. Their experience also made them more aware about future issues, and contributed to the personal growth and maturity of all members (particularly the child's siblings). In addition, there was a significant number of mothers who fully accepted their situation and favourably compared themselves to families whom they perceived to be better off than they were.

3.3.3.3 Summary table of family resilience studies in the Middle East and other Islamic countries.

Table 3.4 summarises all the above studies of resilience among families with chronically ill children in the Middle East and other Islamic countries. The studies investigated various contexts, and employed a range of methods, samples, aims and data analysis techniques.

Table 3.4

Summary of Empirical Studies Covering Family Resilience in the Middle East and Other Islamic Countries

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
Aldosari & Pufpaff (2014): Sources of stress among parents of children with intellectual disabilities: a preliminary investigation in Saudi Arabia.	Descriptive comparative research study.	17 pairs of parents with a child suffering from an intellectual disability in Saudi Arabia.	Multivariate analysis of variance; t-test.	The mothers perceived higher stress levels compared to their husbands. These were related to the overall parent-child relationship, the child's individual characteristics, and the parent's characteristics.
Haimour & Abu-Hawwash, (2012): Evaluating quality of life of parents having a child with disability.	Descriptive quantitative study.	306 families divided into four groups depending on the condition of their child (mental retardation, learning disability, physical disability, and autism) in Arabic countries.	Multiple regression analysis.	The level of resilience of families, as measured by their QOL scores, depended on the type of condition the child suffered from as well as the severity. In order of highest to lowest QOL: learning disability, physical disability, mental retardation, and autism.

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
Kheir et al. (2012): Quality of life of caregivers of children with autism in Qatar.	Descriptive quantitative study.	98 Qatari parents who acted as the caregiver to their children (56 had children suffering from autism, while 42 had a typically growing child).	Chi-square tests; t-test; Pearson correlation coefficient.	There were no significant differences with regards to the quality of life scores among the autism group and the non-autism group. However, the parents of children with autism rated their overall health as poor and likely to worsen as a result of their stress and anxiety.
Lakhani et al. (2013): The impact of caring for children with mental retardation on families as perceived by mothers in Karachi, Pakistan.	Descriptive quantitative study.	54 mothers of children with mental retardation in Pakistan.	T-test; SPSS.	The respondents reported positive contributions to family resilience and their overall functioning as a result of caring for their chronically ill child. In addition, there was a significant amount of those who fully accepted their situation and who had upward favourable comparison with other families.

STUDIES	METHODS	SAMPLE	STATISTICAL APPROACH	KEY FINDINGS
Mohammed et al. (2013): Congenital anomalies among children: knowledge and attitude of Egyptian and Saudi Mothers.	Descriptive comparative research study.	200 mothers (100 Egyptian and 100 Saudi) whose child had any type of congenital anomaly.	T-test; Chi-square tests; Pearson correlation coefficient.	Despite the difficulty that comes with having a child that is chronically ill, the respondent mothers recognise that it is still God's will. These mothers cope through this problem through support from family and close friends, and also being equipped with the knowledge to prevent such an event from happening again should they want to have another child.
Motamedi et al. (2007): A study in depression levels among mothers of disabled children.	Quantitative cross-sectional study.	100 mothers of children with mental or cognitive disabilities in Iran.	Chi-square test; SPSS.	There was a significant correlation between the mother's depression and ability to cope with the type of disability of their child. Seventy- three per cent of the respondents suffered from depression, with 21 per cent having severe depression.

The studies summarised above have been important in informing current understanding of the development and adaptation of young people, as well as their families who are exposed to significant risk, and the various protective factors and processes involved in resilience. These studies also reflect the diversity of approaches to the measurement and methods of assessing adaptation, risk and resilience. Additionally, the resilience studies mentioned discussed shifts in the theoretical understanding of resilience. Developments in family resilience, particularly in the key factors influencing it, will be discussed in the next section.

3.4 Key Factors Influencing Family Resilience

Resilience has been described as a two-factor model incorporating risk and adaptation (Masten & Reed, 2002). It is important to investigate why some people do better than others and demonstrate positive adaptation in the context of risk. Another essential approach is to explore where these differences lie, and what causal agents or predictors are associated with the relationship between adversity and adaptation (Masten & Reed, 2002). There is evidence in the literature supporting the relationship between family resilience and certain factors including the socioeconomic status, type and severity of disease, and family and social relationships (see for example, Aldosari & Pufpaff, 2014; Bellin et al., 2008; Cloutier et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Haimour & Abu-Hawwash, 2012; Kheir et al., 2012; Kilmer et al., 2008; Knestrict & Kuchey, 2009; Lee et al., 2004; Liu et al., 2007; Motamedi et al., 2007; Seltzer et al., 2011; Zashikhina & Hagglof, 2009). The relationship between family resilience and these factors has been well identified in the empirical studies reviewed previously (see for example, Aldosari & Pufpaff, 2014; Bellin et al., 2008; Gerhardt et al., 2003; Kilmer et al., 2008; Seltzer et al., 2011; Zashikhina & Hagglof, 2009). Aside from being the

most commonly occurring themes in the review of the studies, they were also present across the various cultures and contexts.

The first key factor found to influence resilience was the demographic characteristic of the families, particularly their socioeconomic status (Kilmer et al., 2008; Knestrict & Kuchey, 2009; Liu et al., 2007; Seltzer et al., 2011; Zashikhina & Hagglof, 2009). This was observed as a commonly recurring factor, due to the exorbitant expenses commonly associated with caring for a chronically ill child, which includes doctor's appointments, therapy sessions, treatments and medicine. These costs were a huge burden for many families, especially for those who were not well off or those who were living in poverty (Kilmer et al., 2008). The need to care for a chronically ill child and provide for the entire family caused much stress, anxiety and worry for the parents (Liu et al., 2007). This is further exacerbated by them having to do all of these things while maintaining a full time job (Seltzer et al., 2011). Unfortunately, the income they earn may often not be enough (Zashikhina & Hagglof, 2009). Their ability to become resilient and function as a family is consequently hampered.

The second major influence of family resilience was connected to the condition of the chronically ill child, whether it was the type, severity or length of illness (Aldosari & Pufpaff, 2014; Gerhardt et al., 2003; Haimour & Abu-Hawwash, 2012; Kilmer et al., 2008; Motamedi et al., 2007; Seltzer et al., 2011; Zashikhina & Hagglof, 2009). The more severe the condition of the child, or the longer period of time the child suffered from the illness, the more problematic the family was in terms of their resilience and overall functioning (Zashikhina & Hagglof, 2009). For instance, in Motamedi et al.'s (2007) study, they observed a significant relationship between the mother's depression, as well as their ability to cope with adversity, and

their child's disability type. Similarly, Seltzer et al. (2011) observed that parents of children with developmental disorders, compared to parents of children with mental health disorders, suffered much worse outcomes. The reason for this observation was because the severity of the illness often manifested into considerable symptoms or behaviours that brought added stress to the families, which hindered the development of resilience methods (Kilmer et al., 2008). This was also true for cases of comparison between different types of illnesses. For instance, Seltzer et al. observed that conditions such as learning and physical disabilities led to much better resilience outcomes compared to those chronic conditions that had greater impact (e.g., intellectual disability and autism).

The third and most common factor found to influence resilience was the relationships that the family had with each other, as well as with their friends and their community (Bellin et al., 2008; Cloutier et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Kheir et al., 2012; Kilmer et al., 2008; Knestrict & Kuchey, 2009; Lee et al., 2004; Liu et al., 2007). Factors within the family consisted of family cohesion and support from other family members (both nuclear and extended). Parents, grandparents and even other siblings often helped each other cope, through providing comfort and maintaining harmony among the family (Bellin et al., 2008). Additionally, respondents from the study of Liu et al. (2007) stated that they commonly relied on emotional support from their spouse or their other children as a way to assuage their exhaustion, stress and anxiety. Harmonious relationships among family members helped mitigate the adverse effects of stress and anxiety, and acted as a catalyst for developing family resilience (Cloutier et al., 2002; Kilmer et al., 2008; Lee et al., 2004). Similarly, Greeff et al. (2006) stated that when families came together and used their collective strengths to address their stressors, resilience

was fostered in the family, as well as the individuals themselves. Community factors include social support external to the family, such as from other community members (Masten & Reed, 2002), relationships with competent social adults or peers, and involvement in social organisations (Masten & Reed, 2002). Friendships also helped them develop resilient behaviours. Aside from the emotional support they received from their friends, these relationships also allowed them the opportunity to temporarily forget their problems and distress (Bellin et al., 2008). Liu et al. (2007) also explained that families sharing their experiences with their neighbours and friends not only helped others understand their difficult situation, but it was also a way for them to release their frustrations and worries.

The reviewed body of literature made similar observations to Antonovsky's salutogenic model (1987), as well as Bronfenbrenner's ecological model (Lovat et al., 2010; McCubbin & McCubbin, 2001). The former, Antonovsky's salutogenic model, was proposed to promote understanding of the relationship among stressors, health and coping, with the aim of explaining how some individuals remain healthy despite stressors in their everyday living. Antonovsky (1987) proposed that generalised resistance resources (wealth, strength, culture stability, social support) could promote a sense of coherence. This model particularly explains the strong association between socioeconomic status and emotional and social support with resilience in the majority of empirical studies reviewed. Antonovsky focused on the impact of social conditions on people's health in society, and that the key to coping was embedded in society and in people who cared about each other. The salutogenic model is significant, as the influence of society is very important in the Arab world, especially Saudi Arabia. Hence, this would affect the way Saudi families with chronically ill children choose their coping strategies.

Similarly, Bronfenbrenner's ecological model (Lovat et al., 2010) stated that overall well being is significantly predicted by the social contexts in which families are embedded. Their resilience is also a function of the quality of relationships among individuals, family and institutional systems. This further emphasises that resilience is a static, individual trait (Lovat et al., 2010).

3.5 Conceptual Models of Resilience

This study emphasises the need for further exploratory research regarding this topic in Saudi Arabia. This is especially important due to Saudi Arabia (and most nations in the Middle East region) being a collectivist society, as discussed in the studies of McCabe et al. (2008), as well as Pellegrini and Scandura (2008). This highlights the preferences for communal existence and the emergence of patriarchal leaders. It is also worth noting that religion may be a key differentiating factor in exploring the factors that lead to family resilience (McCabe et al., 2008; Seccombe, 2002; Ungar, 2004).

A significant portion of the research undertaken on the concept of resilience emphasises the strengths present in individuals or family units, who have shown high degrees of resilience in overcoming adversity (Lee et al., 2004). The concept of resilience in most of the previous research has been defined and studied in terms of individual personality traits and/or family handling techniques that allow either the child or the family to survive traumatic life experiences, such as chronic illness (Ganong & Coleman, 2002; Walker et al., 2004). The basic concept of resilience in the past was that resilient individuals develop simply due to inherent traits or biological hardiness, which was simply the outcome of their personal efforts and genetic characteristics (Walker et al., 2004).

Even though personal resilience was the basis of the construct of resilience, the family unit as a responsible source of resilience development has been the subject of numerous research projects in the last two decades (Lee et al., 2004; Luthar et al., 2000). The recent research on family resilience has shown that the concept of resilience is multidimensional (Luthar et al., 2000). In addition, many researchers believe that resilience may be a veridical construct, instead of mythical one (Luthar et al., 2000). The concept of resilience currently includes different adaptation factors and domains that have many inconsistencies. This has made the delineation process of best indicators or most important impact factors of resilience development in both family and individual studies relatively complex (Luthar et al., 2000).

Families constantly face challenges that are quite threatening, and family resilience is important in determining how families cope with various adversities. Research has shown there are two basic components of family resilience: family protective resilience and family recovery resilience (Lee et al., 2004). According to Lee et al. (2004), family protective resilience refers to the strategies employed within families to keep, deal with, and avoid the forces that threaten the family unit. Family recovery resilience also refers to the various ways in which the family can reorganise themselves after a stressful period. In instances of stress, families become more prone to risk factors that affect the normal functioning of a family, further threatening to encourage other factors that might hasten the complete dissolution of the family (Lee, et al., 2004). Certain occurrences, introducing changes, or even situations within the family that promote stress, place the family at risk of disintegration.

A combination of factors predisposes individuals to look for emotional and psychological strength from the family environment (Lee et al., 2004). A lack of this leads to the interaction of such individuals with the community becoming dysfunctional. Central to family resilience are two aspects that are interrelated and provide a point of connection between family protective resilience and family recovery resilience (Lee et al., 2004). Firstly, 'adjustment' refers to the activities undertaken by a family in times of crisis in an attempt to ensure that the family stays healthy physically, emotionally and psychologically.

In contrast, 'adaptation' refers to the ability of the family to structure approaches that ensure the family recovers from a particular crisis (Lee et al., 2004). According to Lee et al., the family as the basic unit of the society should always be protected and equipped with enough strategies to survive the various adverse circumstances it faces. Therefore, family resilience is an important consideration when addressing the challenges family members face when their child is suffering from chronic illness. Each family will adopt different strategies when dealing with these situations associated with this (Zand, 2011). These approaches will depend on various aspects, including the nature and strength of relationships in the family, past experiences, as well as the culture and beliefs of the family as a unit (Lee et al., 2004; Zand, 2011).

In recent times, the concepts, theory and research in the field of resilience have been applied to the family unit as a system. The research undertaken on family resilience has tried to determine which processes affect the development of positive outcomes when families face adversity or crisis. The risk factors involved, the theory of family stress and coping, as well as the part social support plays, and connections, all play a part in understanding family resilience.

Further, family stress theory, which was described by the 'Family Adjustment and Adaptation Response' (FAAR) model, focuses on the active processes that a family unit may conduct to create a balance between family demands and capabilities (Patterson, 2002). The interaction among these factors significantly determines positive adaptation (Patterson, 2002) (see Figure 3.1). Family demands include both normative and non-normative causes of stress, continuous family strains (such as a child's chronic illness), as well as regular disturbances in their daily lives.

Most of the demands mentioned in the FAAR model can be considered risk factors (Patterson, 2002). Family capabilities refer to both the tangible resources that the family possesses, as well as the range of psychosocial handling behaviours that the family uses to develop resilience. These capabilities can be termed as the 'protective factors'. Together with the risk factors and protective capabilities, the social or environmental context has to be considered (Patterson, 2002).

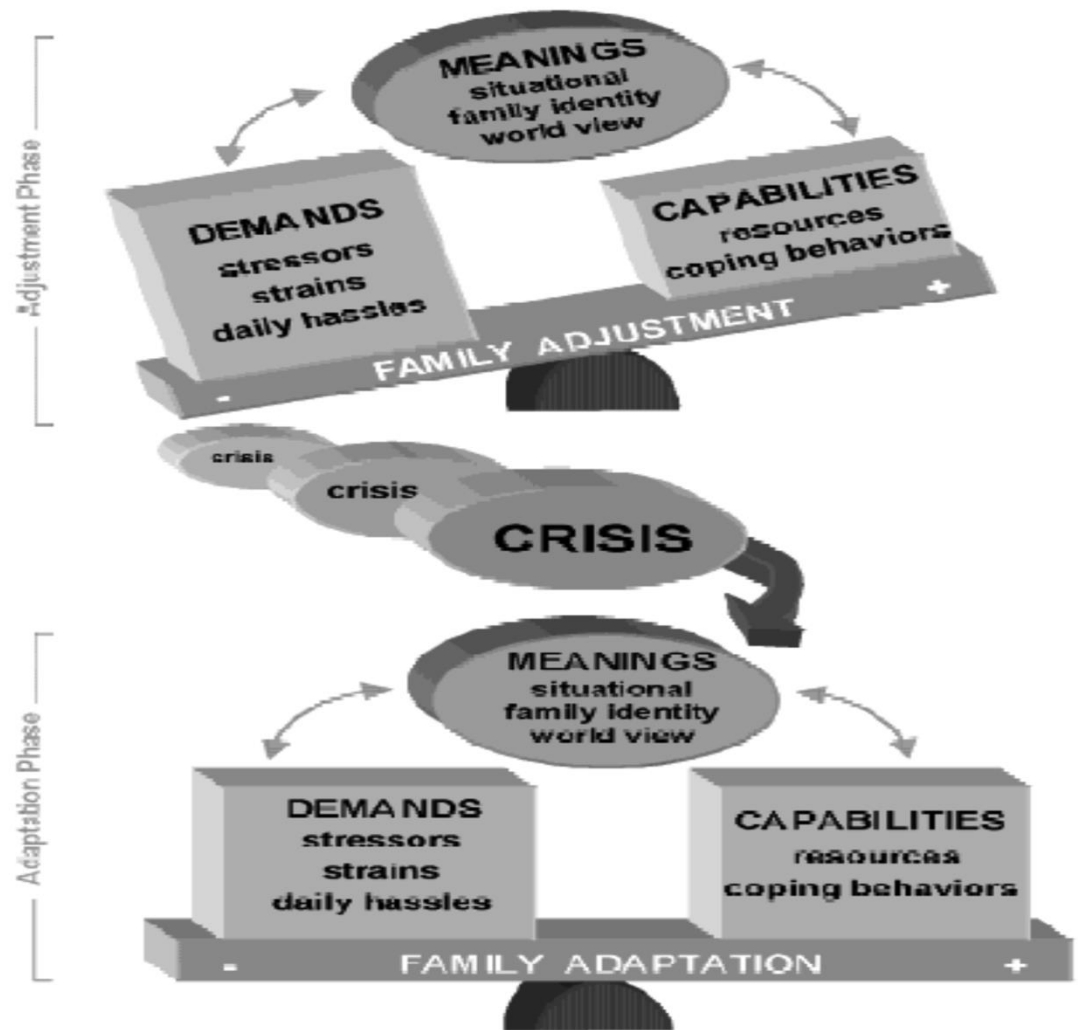


Figure 3.2: The FAAR model for concepts involved in family resilience

(Patterson, 2002).

3.6 Operationalising Resilience

Beyond providing a general outlook on resilience through this literature review, it is also essential to outline how the concept of resilience will be operationalised in this study. The construct of resilience will be investigated using a recently developed methodological approach for the operationalisation of resilience (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006). Using this approach, resilience will be

conceptualised according to both the level of stress (high or low) experienced by participants, as well as their adaptation (positive or negative). Participants' adaptation will be assessed as either positive or negative, according to the assessment of internalising and externalising symptoms.

Participants will then be further classified into four groups, according to combinations of high or low stress and positive or negative adaptation. Participants who experience high levels of stress, but report a positive adaptation (low internalising and externalising symptoms) will be classified as resilient. Three other groups will also be classified according to their levels of stress and adaptation. 'Negative expected' participants are those who report high levels of stress and, as might be expected, negative adaptation (high internalising and externalising symptoms). Participants who report low levels of stress and corresponding positive adaptation (low internalising and externalising symptoms) will be classified as 'positive expected'. Participants classified as 'poor copers' will report low stress but high externalising and internalising symptoms. This will indicate an inability to deal with lower levels of stress. The model used to operationalise resilience in this study will be further described in Chapter 4 (Methodology).

3.7 Summary

This chapter has defined and identified resilience as it applies to families with a child suffering from a chronic illness. The concept of family resilience was also explored through the lens of various contexts and cultures from around the world, with a particular focus on the Middle East and Islamic countries. This built a comprehensive understanding of the concept of resilience and its importance to families, individuals and communities.

Exposure to risk is one of the two major dimensions of resilience. Many and varied risk factors have been identified in the resilience literature. Risk factors can have a direct or indirect effect on the individual and often occur together. Those most at risk appear to be individuals who experience a multitude of risk factors—or cumulative risk—over time. Finally, an understanding of family resilience and how this can maintain, build and strengthen families with chronically ill children was discussed.

Taking these into account, the review of related literature was able to find existing gaps in the body of research, particularly with unexplored topics that need to be defined and investigated further. A major unexplored area that the study will address is the paucity of research regarding resilience among Saudi Arabian families with a chronically ill child. This research hopes to fill these gaps, with the findings to be obtained and analysed in succeeding chapters.

The significant gap in the literature regarding resilience in the Saudi Arabian context was notable. In general, there is a sizeable scarcity of articles that discuss family resilience in a non-Western perspective. These gaps may be addressed in future studies. However, this research will emphasise the context of Saudi Arabia. For the purposes of this study, related concepts such as the collectivist nature and conservative leanings of Middle Eastern or predominantly Islamic countries were discussed in place of research that explicitly tackled family resilience.

Following this literature review, the next chapter will describe the methodology of the present study. This chapter will consist of an overview of the variety of methods employed within the thesis, a brief discussion of the setting and the study's ethical considerations.

Chapter Four: Research Design and Methodology

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Chapter 4 : Research Design and Methodology

4.1 Introduction

A descriptive explorative cross-sectional research design was used to determine the resilience of Saudi families with chronically ill children. This method was considered an appropriate way of approaching the topic to provide a comprehensive understanding of this phenomenon. To date, no studies have been undertaken to determine patterns of coping among Saudi families with chronically ill children. The focus of this chapter is to describe the research methodology, including the setting, the sampling method and the inclusion and exclusion criteria.

The research design for this study consisted of two phases of data collection. This chapter will describe the quantitative research instrument, the validity and reliability of the research instruments and the process of the quantitative data collection and analysis. Part two of this chapter will describe the semi-structured face-to-face interviews with a sample of registered paediatric nurses and parents of chronically ill children. The ethical considerations for the conduct of this study are also discussed and described.

4.2 Research Methodology

This descriptive explorative cross-sectional research study was designed to describe and explore the concept of resilience and the coping patterns of Saudi families with chronically ill children. A two phase method was used to determine the approaches employed by these families to become resilient and the factors that led them to emerge as stronger in the face of adversity. This method enabled detailed and specific understandings of the interactions among the variables of interest and captured the complexity of the relationships that existed between them.

Burns and Grove (2005) defined a research design as the 'precise manner for the conduct of the study that maximises control over factors that could interfere with the study's desired outcome' (p. 40). It is the plan or framework of the study (Iacobucci & Churchill, 2010). The research design directs and systemises the data collection and analysis. Leedy and Ormrod (2010) add that research designs connect questions to data. This research had two methods of gathering data: quantitative and qualitative. Both quantitative and qualitative research methodologies have their limitations. Combining the two helps address their respective weaknesses (Denzin & Lincoln, 2009). The purpose of using this approach was to validate the results, and bring together the strengths of both the quantitative and qualitative data, to provide a better understanding of the research problem (Salehi & Golafshani, 2010). The advantage of using this approach was to provide a comprehensive response to the research questions that could not be obtained with a single approach. This approach would provide a better understanding of the phenomenon of resilience in Saudi families. Thus, this study had two phases, a questionnaire and a face-to-face semi-structured interview. The questionnaire was undertaken with Saudi parents of chronically ill children, to gather quantitative results about the sample. Following this, interviews with Saudi parents and registered paediatric nurses gained a different perspective.

The quantitative approach was used to examine and identify the relationships between the independent and dependant variables through a survey questionnaire distributed to collect the demographic data and elicit information to identify the factors that led to resilience of Saudi families with chronically ill children. The qualitative approach used semi-structured face-to-face interviews with registered paediatric nurses and Saudi families of chronically ill children to provide in-depth

knowledge to better understand the phenomenon. Figure 4.1 below illustrates the approach used in this study.

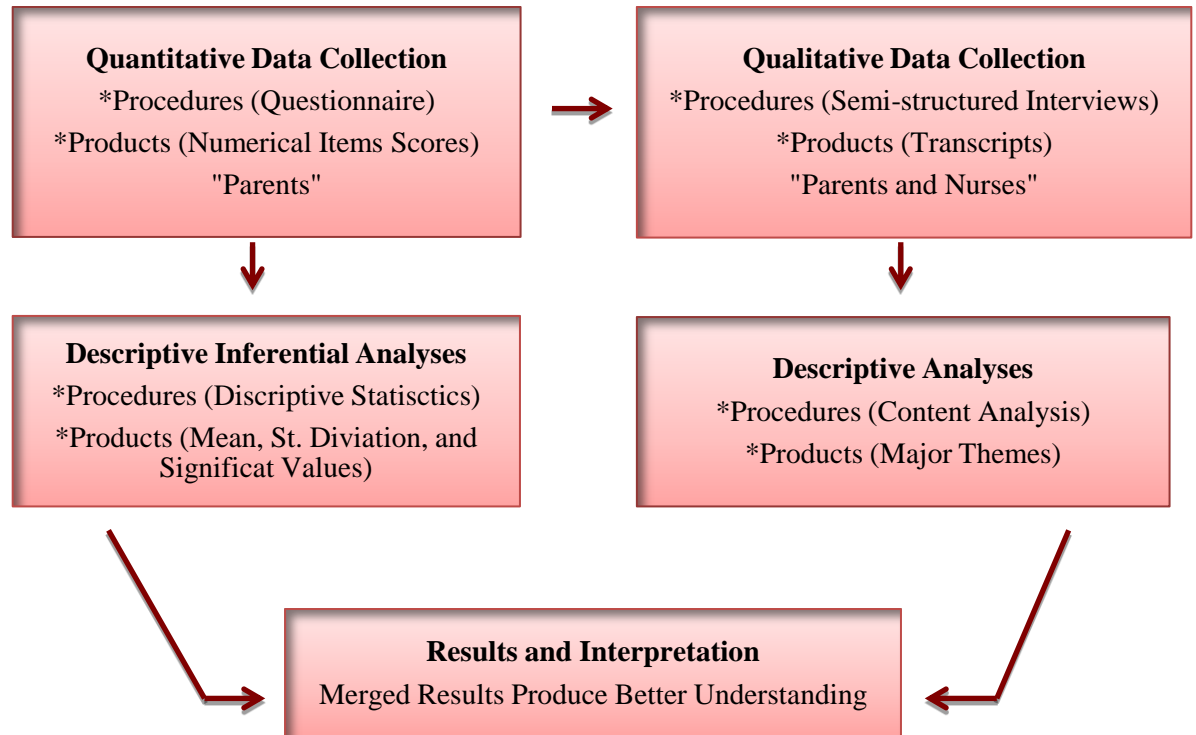


Figure 4.1. The approach used in this study.

This study aims to describe and explore the concept of resilience in Saudi families who have chronically ill children. The specific objectives of this study are as follows:

1. To explore and identify factors that contributing to resilience of Saudi parents when faced with the adversities of chronically ill children.
2. To explore the relationships between family resilience and a chronic illness of a sick child.

3. To investigate the type of support Saudi families receive from the health care system, visiting health care professionals, religious leaders, social and family networks.
4. To explore nurses' perspectives on the support offered by the Saudi health care system to these families.

From the aims described above, the following major questions relevant to the current study context have emerged:

1. What are the factors associated with resilience among Saudi families with chronically ill children?
2. What are the relationships between family resilience and the chronic illness of a sick child?
3. What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities associated with chronically ill children?
4. How does the Saudi health care system assist Saudi families in adjusting to the adversity associated with chronic health conditions?
5. What factors contribute to resilience in Saudi families?

4.3 Research Setting

The study was conducted in three main public hospitals in the Jeddah region. These hospitals included: Maternity and Children Hospital (MCH), King Abdul Aziz University Hospital (KAAH) and King Faisal Specialist Hospital and Research Centre (KFSH&RC). Permission to conduct the research was granted by the Ethics Committee of RMIT University, the MOH and each hospital's administration department (see Appendices A, B, C, D & E). All of these hospitals have government-supported budgets, and they provide free medical care for all Saudi and non-Saudi patients, including comprehensive care for both inpatients and outpatients

(MOH, 2011). Table 4.1 below provides the distribution of chronic paediatric beds in each of the three hospitals in 2012.

Table 4.1

The Total Number of Beds in General and the Number of Beds in Paediatric Wards in Each Hospital

Hospital	Total Number of Beds	Beds in Paediatric Wards	Chronic Paediatric Beds
Maternity & Children's Hospital (MCH)	400	90	45
King Abdul Aziz Hospital (KAAH)	895	147	70
King Faisal Specialist Hospital and Research Centre (KFSH&RC)	440	57	37

4.4 Sampling Strategy

Sampling is defined by Johnson and Christensen (2008) as the process of drawing a sample from the population. The target participants in this research were Saudi parents (18 years and over) living with chronically ill children aged 6 months to 16 years, and registered paediatric nurses (over the age of 21) from the three main public hospitals in the Jeddah region. To clarify, only families with children who have chronic long-standing illnesses (> 3 months of hospitalisation per year) (Hockenberry & Wilson, 2011) were invited to participate in this study. Families whose children had been recently diagnosed with an acute illness or a recently diagnosed chronic illness ($<$ than one month) (Hockenberry & Wilson, 2011) were excluded. This study used a convenience sampling strategy, and all subjects participated voluntarily. This sampling strategy was used as it provided easy

accessibility and the ability to meet the inclusion criteria for subjects (Ary, Jacobs, Sorenson & Razavieh, 2009).

4.4.1 Inclusion criteria.

The following eligibility criteria were formulated for parents participating in this study:

- Saudi parents (18 years and over).
- Having children with chronic long-standing illnesses (> 3 months).
- Being able to write and read either Arabic or English to complete the questionnaire and participate in the interview.

The following eligibility criteria were formulated for the nurses participating in this study:

- Registered paediatric nurses (21 years and above).

4.4.2 Exclusion Criteria

The researcher excluded:

- Non-Saudi parents.
- Families whose children had been recently diagnosed with an acute or chronic illness (< one month).

4.5 Recruitment

The recruitment process began in January 2012 and continued through to September 2012. After obtaining all ethical approvals (further explained in Section 4.8), the data collection procedure took place as follows.

First, formal letters were sent to the directors of nursing at the selected three hospitals seeking approval for data collection. Copies of ethical approvals and a summary of the study were also attached to the request. The researcher then contacted the head nurse and the ward manager of each selected paediatric unit

separately to organise the data collection process and clarify any issues related to the study. The researcher discussed with all paediatric unit head nurse and managers regarding the following: the purpose of the study, what the two phases included, the method of data collection, the time required to participate in each phase, and the criteria of Saudi parents and registered paediatric nurses required for inclusion in the study. In addition, the steps required to complete Phase 1 and Phase 2 of the study were agreed upon. The Phase 1 survey questionnaire distribution was discussed and the Phase 2 data, time and venue were arranged. The unit head nurse and manager then helped in preparing the list of chronically ill children and paediatric nurses' names. Chronically ill children and paediatric nurses were then screened for their eligibility to participate in the study.

After that, the study was advertised through posters placed on notice boards of the paediatric wards in the three hospitals (see Appendix F). Envelopes containing a plain language statement (see Appendix I) explaining the importance of the study, the questionnaire (see Appendix M), and invitation letters to participate in a face-to-face interview (see Appendix L), a card with the researcher's contact details, and consent form (see Appendix K) were handed to the parents of chronically ill children (identified by the head nurses and ward managers) on the wards by the researcher. Return boxes were labelled 'Saudi Family Resilience' and placed in the nursing station of each paediatric ward in the three hospitals. All the documents provided in the envelopes were in both Arabic and English.

The parents were requested to complete the anonymous questionnaire, place it in the envelope provided and return it to the box labelled 'Saudi Family Resilience' on each nursing station. All Saudi parents who were willing to

participate in the interview were required to contact the researcher by phone or email to organise a time for the face-to-face interview.

Letters were also sent by the researcher to the nursing paediatric wards in each hospital inviting the ward nurses to participate in this study (see Appendix H). Envelopes containing a plain language statement (see Appendix J), consent form (see Appendix K) and a card with the researcher's contact details were left in each ward for the nurses to contact the researcher by phone or email to arrange a face-to-face interview. The following sections explain the two phases approach in more detail.

4.6 Phase One: Quantitative Approach

Three-hundred-and-fifty-eight envelopes were distributed across the three hospitals to Saudi parents with chronically ill children. A total of 122 Saudi parents completed and returned the questionnaires via the return boxes (see Table 4.2), giving a response rate of 34 per cent.

Table 4.2

The Total Number of Participants in Each Hospital

Hospital	Total Number	Participants' Response
Maternity & Children Hospital (MCH)	78	30
King Abdul Aziz Hospital (KAAH)	140	52
King Faisal Specialist Hospital and Research Centre (KFSH&RC)	140	40
Total	358	122

4.6.1 Research Instrument

Questionnaires are the most common instruments used by researchers to collect data (Polit & Beck, 2008). There are a number of questionnaires available to

measure individual resilience. However, when choosing a questionnaire, care needs to be taken in assessing and considering the appropriateness of the questionnaire and the characteristics of the target population (Polit & Beck, 2008). According to Polit and Beck (2008), 'if non-English-speaking participants are included in the sample, then the selection of the instrument may be based on the availability of a translated version' (p. 295). The researcher reviewed Western resilience questionnaires (for example: 'The Resilience Questionnaire', 'The Resilience Assessment Questionnaire', 'The Personal Resilience Questionnaire', 'The Resilience Advantage Questionnaire', 'The Resilience Scale', 'The Resiliency Scale', 'The Resilience/Stress Questionnaire') with her supervisors and found that these questions were neither suitable nor applicable to use in the Saudi culture, and most had poor psychometric properties.

It is also important to note that resilience is a complex construct to measure, and direct self-report measures are arguably methodologically flawed. The approach in this study was based on a method developed in association with Reece for operationalising resilience (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006). This consisted of using valid and reliable assessments of the two constructs that make up resilience—stress and adversity—and the adaptive response to the stress and adversity. According to this design, participants will be classified into four resilience groups based on combinations of stress (high or low) and adaptation (positive or negative). Participants who experience high level of stress and a positive adaptation are doing well (i.e., *resilient*). The classification of *negative expected* participants are those who report high levels of stress and, as might be expected, negative adaptation (high internalising and externalising symptoms). Participants who report low levels

of stress and corresponding positive adaptation (low internalising and externalising symptoms) will be classified as *positive expected*. Participants who are classified as *poor copers* will report low stress but high externalising and internalising symptoms. More explanation of operationalising resilience will be explained in the next section.

In this study, stress and adversity had been assessed based on demographic information about the parents and their chronically ill children. A QOL scale was used to measure the response to stress and adversity. A social support questionnaire (SSQ) and self-efficacy scale (GSE) were predictors of the resilience classifications. This is a sound method that has been used with numerous studies (Adger, 2000; Carpenter, Walker, Anderies & Abel, 2001; Schembri, 2007; Thomas, 2007). Translating the resilience questionnaires was not an issue as a direct measure of resilience was not required; the study operationalised resilience based on what people reported through their responses to the questionnaires about their levels of stress and adversity and their responses to those experiences. Although all current resilience surveys were identified and evaluated, it was decided to adopt the approach of operationalising resilience, based on a theoretical representation of the construct.

Thus, it was determined to use the following scales and questionnaires in this study: 'Quality of Life Scale' (QOL) (Flanagan, 1982), the 'General Self-Efficacy Scale' (GSE) (Schwarzer & Jerusalem, 1995), and the 'Social Support Questionnaire' (SSQ) (Sarason, Levine, Basham & Sarason, 1983) in addition to demographic data has established validity and reliability. These scales and questionnaires have established reliability and validity (which is discussed below) in Middle Eastern research studies (Abdel Hai, Taher & Abdel Fattah, 2010; Al Khatib, 2012; Duvdevany & Abboud, 2003; Elsheshtawy & Abo Elez, 2011; Hoffman,

Ushpiz & Levy-Shiff, 1988), as they have been translated into many languages including Arabic. These questionnaires and scales identify stress and coping levels, as well as the QOL of individuals living with a chronically ill child. The added demographic part of the questionnaire was translated by a certified translator into Arabic (see Appendix P). Approval to use these questionnaires was not required from the authors, as all these questionnaires are published for use by researchers on the internet. All participants were informed that they were able to choose to respond to either the Arabic or English version of the questionnaire.

Demographic information was collected in relation to the age of parents, gender, relationship to the chronically ill child, marital status, occupation, income, highest educational level and number of children in the family. Information on the structure of the family was provided by questions about the age, gender and living arrangements of all children, as well as identifying which of the children were healthy or sick. Parents provided details on the child's chronic illness, the duration of the child's chronic illness, time spent in caring activities for their sick child, family time spent together, and respite help and support provided to the family.

GSE (Schwarzer & Jerusalem, 1995) was used to assess a general sense of perceived self-efficacy, as well as adaptation after experiencing stressful life events. This scale has been translated to 33 languages including Arabic. The construct of self-efficacy reflects an optimistic self-belief that one can perform difficult tasks, or cope with adversity in various domains of human functioning (Schwarzer, 1992). Perceived self-efficacy facilitates goal setting, effort investment, persistence in the face of barriers and recovery from setbacks. It can be regarded as a positive resistance resource factor. Ten items are designed to tap this construct. Each item refers to successful coping and implies an internal-stable attribution of success. The

criterion-related validity of this scale is documented in numerous correlation studies (Koring et al., 2012; Parschau et al., 2013), where positive coefficients were found with favourable emotions, dispositional optimism and work satisfaction. Negative coefficients were found with depression, anxiety, stress, burnout and health complaints. The scale requires four minutes on average to complete. Responses are made on a four-point scale, which includes: not at all true, hardly true, moderately true and exactly true. Scale scores were calculated, and a total self-efficacy score was derived for each participant.

To assess the social support experienced and perceived by the participants of this study, the SSQ (Sarason et al., 1983) was administered in order to assess perceived availability of social support and satisfaction with the social support received. The SSQ is a 12 item self-administered scale assessing the integration of families within the community; it views the community as a source of support, and assumes that the local community can provide emotional, self-esteem and networking support. Items are rated a six-point Likert scale, ranging from 'Strongly Disagree' 1, to 'Strongly Agree' 6. A total SSQ score was calculated for each participant. The Arabic version of this questionnaire was translated and back translated by professional translators (see Appendix P).

Finally, the QOL (Flanagan, 1982) questionnaire was administered. This is a 16-item instrument that measures six conceptual domains of quality of life: 1) material and physical well being; 2) relationships with other people; 3) social; 4) community and civic activities; 5) personal development and fulfillment and recreation; and 6) independence, doing for oneself. The QOL instrument is scored by summing the items to make a total score. Subjects are encouraged to fill out every item even if they are not currently engaged in the stated activity (e.g., they can be

satisfied even if they do not currently participate in organisations). The QOL scale was originally developed and validated for English-speaking populations in the USA and it has been also translated and validated in 16 different languages: Arabic, Danish, Farsi, French, German, Greek, Hebrew, Icelandic, Italian, Mandarin Chinese, Norwegian, Portuguese, Spanish, Swedish, Thai and Turkish.

4.6.2 Method of operationalising resilience.

4.6.2.1 Stage 1: operationalising stress and adversity.

The approach to operationalising resilience consisted of first obtaining a measure that represented the overall level of stress and adversity for each participant. While the research instruments used in this study did not directly measure stress and adversity, specific individual items to identify stress and coping were selected from the questionnaires, based on findings of previous studies (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006). These identified that the financial burdens of illness, and the difficulties associated with raising a child with a chronic illness have negative effects on families and cause a high level of stress, not only for the parents, but for all family members (Freedman & Boyer, 2000; Parish & Cloud, 2006). Block and colleagues (2002) reported that families with chronically ill children may be likely to face high levels of stress associated with life adversities. Families with low income, higher unemployment rates and lower levels of education are even more prone to stress-related adversity. Caring for chronically ill children at home can be emotionally, physically, psychologically and financially exhausting for the caregiver. Caregivers require temporary relief from the burden of day-to-day care of these children (O'Connor, Vander Plaats & Betz, 1992). Thus, eight individual questions from the demographic questionnaire supported by evidence relate to: occupation,

income, education, number of sick children with a chronic illness in each family, type of child's chronic illness, duration of child's chronic illness, the time parents spent in caring activities for their sick child, and whether the family received respite help. These were selected as measures of stress and adversity.

Then, the following values associated with these items were used to create the index of stress and adversity. For the variable occupation, 0 was scored for unemployed and 1 for employed; for the variable income, 0 scored for 24,000–45,000 SR annual income and 1 for 46,000 SR and above; for the variable education, 0 was scored for primary or secondary and 1 for technical or tertiary educational level; for the number of sick children, if a family reported two sick children, they scored 2 in the index of stress and adversity, 1= having one child suffering from chronic illness, 3=3 children, 4=4 children, and 5=5 children suffering from chronic illness; for the duration of the child's illness variable, (1=1-2 years, 2=3–4 years, 3= above 5 years and 4= from birth), for the variable time spent in caring activity, (1=less than 1 hour, 2= 2–3 hours, 3= 4–5 hours, 4= more than 6 hours, 5= continues care), and for the variable respite help, if the family reported that they were receiving respite help, they scored 1 and if not, they scored 2. The scores for each demographic item were calculated and added together to obtain a final total single score that inferred the level of stress and adversity of the Saudi parents in this sample (see Table 4.3).

Table 4.3

The Total Level of Stress and Adversity

Demographic Variable	Scores
Occupation	0= Unemployed 1= Employed
Income	0= 24,000–45,000 SR 1= 46,000 SR and above
Education	0= Primary or Secondary 1= Technical or Tertiary
Income	0= 24,000–45,000 SR 1= 46,000 SR and above
Number of Sick Children	1= 1 child 2= 2 children 3= 3 children 4= 4 children 5= 5 children
Duration of Illness	1=1–2 years 2=3–4 years 3= Above 5 years 4= From birth
Time Spent in Caring Activity	1=less than 1 hour 2= 2–3 hours 3= 4–5 hours 4= More than 6 hours 5= Continues care
Respite Help	1= Yes 2= No

4.6.2.2 Stage 2: operationalised adaptation.

At stage two, a score for adaptation to stress and adversity was taken, which was from the QOL scale. At the end of this process, each parent had a single score that represented their total level of stress and adversity, and a single score that represented their adaptation to that stress. The first score was derived from the demographic variables, as described above; the second score was taken from the

QOL measure. The score for QOL and the total stress and adversity scores were used to indicate the level of QOL and stress and adversity experienced by each parent, which was then used to classify participants into categorical stress and QOL groups. These results were then used to classify participants into resilience groups. Scores on the individual scores obtained from each participant on both the stress and adversity and QOL scores were ranked from highest to lowest.

Two statistical criteria for classifying participants into stress and QOL groups were used. Stress groups were created based on both median splits and quartile splits; this was so that groups could be formed based on varying levels of stress and adversity. The first criterion of stress involved classifying participants into two groups based on the median of above or below 50 per cent for the sample. The second criterion was based on the quartile range, with those subjects in the Q1 range having the lowest level of stress and Q4 having the highest. The same process was carried out for the QOL scores; QOL groups were obtained from both median splits and quartile splits. The groups were rank ordered and two groups were developed based on the median score with 50 per cent above and 50 per cent below. A quartile split was also used. Hence, at the end of this process there were two group classifications for each of stress and adversity, and QOL: one classification based on median splits, and one based on quartile splits.

To create resilience groups, every combination of the stress and QOL life groups was cross-tabulated, with four labelled groups in each cross-tabulation. These four possible combinations in each cross-tabulation were labelled in the following way: 1=resilience (high stress, high quality of life), 2=low QOL, high stress, 3=at risk (low QOL, low stress), 4=high QOL, low stress. All possible combinations of the cross-tabulation of stress and adversity groups were examined with the goal of

identifying one that had an adequate sample size in each resilience group. The particular combination used will be described briefly in the following Chapter 5 ('Quantitative Statistical Analyses').

4.6.2.3 Stage 3: classification model of resilience.

The method of operationalising resilience applied in this study (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006) was based on the principles of the full classification model described by Masten and Reed (2002), similar to that used by Luthar (1991) and Masten et al. (1999). According to this design, participants were classified into four groups based on stress and adversity (high or low) and QOL (high or low). The participants with high stress and adversity and high QOL are the resilient group; those with low stress and adversity, high QOL are doing well and are able to deal with their lives; those with high stress and Low QOL is what would be expected; the group with low stress and adversity and low QOL are of more concern, and seem to reflect people with very poor coping skills. Figure 4.2 illustrates the division of these groupings according to stress and adversity category and QOL category. It further relates these groupings to a resilience label. Detailed statistical description and analysis will be described briefly in Chapter 5.

		Stress & Adversity	
		Low	High
QOL	High	Low Stress & Adversity High QOL	High Stress & Adversity High QOL = Resilience
	Low	Low Stress & Adversity Low QOL	High Stress & Adversity Low QOL

Figure 4.2: Classification of groups based on high and low stress & adversity and QOL.

4.6.3 Validity and reliability.

Validity and reliability are important concepts in data collection research instruments (Bryman, 2008; Johnson & Christensen, 2008). Validity is an essential criterion to evaluate the research quality (Cohen, Manion & Morrison, 2010). It refers to the capacity of a research tool to measure what it is ideally intended to measure, and the degree to which an instrument measures what it is supposed to measure (Polit & Beck, 2008). Reliability and validity are not independent qualities of an instrument (Polit & Beck, 2008). Reliability is also a crucial criterion in evaluating the quality of research (Cohen et al., 2010). According to Creswell (2002), reliability means that ‘individual scores from an instrument should be nearly the same or stable on repeated administrations of the instrument, they should be free from sources of measurement error, and they should be consistent’ (p. 180). It ensures that the research instrument—in this study a survey questionnaire—is

consistent in that individual scores can be replicated; a quality known as stability (Leedy & Ormrod, 2010).

To evaluate the content validity of the instruments used in this study, the researcher consulted an expert panel to review and rate the instruments of the survey questionnaire (see Appendix G).

The study questionnaire was designed in English and translated into Arabic. The questionnaire was tested for face and content validity by an expert panel composed of three paediatric head nurses and two academic nurses external to the main study, who are working in the KSA. All comments from the expert panel were considered, and the applicability of the survey, as well as the clarity of the questions, was known. The researcher's supervisors and the five members of the expert panel approved the final version of the questionnaire as suitable to gather data for this study.

4.6.4 Pilot test.

According to Burns and Grove (2009), some of the reasons for doing a pilot test are to determine whether the proposed study is feasible, to identify any potential problems with the research design, to examine the validity and reliability of the research instruments, and to give the researcher more experience with the research methods.

A pilot study was conducted in late January 2012, at KAAH to check the questionnaire for timing, clarity, accuracy and cultural suitability prior to conducting the main study. Five mothers who were independent of the main study and met the inclusion criteria responded to the questionnaire. The results of the pilot test showed there were no difficulties understanding or answering the questions. It took around

15 to 20 minutes to complete the survey questionnaire. Therefore, the researcher did not need to adjust or change the questionnaire.

4.6.5 Quantitative data collection.

In this study, the data collection commenced after ethics approval was granted from the Human Research Ethics Committee at RMIT University (RMIT) (see Appendix A). In Saudi Arabia, the High Authority of the Nursing Department in the MOH granted their approval to conduct the study in Ministry hospitals (see Appendix B). Moreover, an approval from the Maternity and Children Hospital (MCH) (see Appendix C), King Abdul Aziz University Hospital (KAAH) (see Appendix D), and King Faisal Specialist Hospital and Research Centre (KFSH) (see Appendix E) were granted and attached to the application for ethics approval in Saudi Arabia.

The researcher visited each hospital in January 2012 and met the nursing director to give a brief explanation about the purpose of the study. Posters were placed on the notice boards of the paediatric nursing wards in the three hospitals (see Appendix F). Two weeks after the study was advertised, the researcher met with the head nurse and manager of the paediatric wards in each of the selected hospitals and asked them to indicate parents with chronically ill children who met the eligibility criteria of the study. The researcher visited the wards three times per week for nine months to distribute the envelopes to eligible parents. Three-hundred-and-fifty-eight parents of chronically ill children in the three hospitals were handed envelopes over those nine months. The participants were required to complete the anonymous questionnaire, place it in the envelope, and return it to the box, which was labelled as 'Saudi Family Resilience', that had been placed in the nursing station in the paediatric wards of each hospital.

Subsequently, the researcher collected all the completed questionnaires from all boxes in the three hospitals and stored them in a secure area for data entry and analysis. According to RMIT University protocol, these data were kept in locked compartments during transcription to a password protected file. Participants who were willing to participate in the face-to-face interview were asked to contact the researcher by phone number or email to organise a suitable date and time to meet.

4.6.6 Quantitative data analysis (descriptive inferential analysis).

The quantitative data was analysed using SPSS Version 20.00 software. There were no missing values in the completed survey questionnaire. The quantitative statistical analyses of the study were divided into two main sections: the first section incorporated descriptive statistics and data were presented in the form of frequencies, percentages, means (M) and standard deviations (SD). The second section included inferential statistics involving comparisons between two variables and one-way ANOVA for comparisons between more than two variables. Correlations were used and a classification model was used to determine resilience status based on scores on stress and adversity and quality of life (QOL).

4.7 Phase Two: Qualitative Interview Approach

4.7.1 Research instrument.

The semi-structured face-to-face interviews were designed to gain in-depth understanding of what the concept of resilience means to Saudi families with chronically ill children. According to Liamputtong (2009), using interviews for data collection is an effective tool for gaining in-depth information about a concept and further explains and confirms the research findings. An interview is a purposeful discussion between two or more people used to collect valid and reliable data relevant to research questions and objectives (Saunders, Lewis & Thornhill, 2009).

Collis and Hussey (2009) define an interview as a method of collecting data in which participants are asked questions to find out what they do, think or feel.

Creswell (2008) argued that interviews 'permit participants to describe detailed personal information' (p. 226). The face-to-face interview is commonly used as a data collection tool in health sciences research to gather information from interviewees (Ryan, Coughlan & Cronin, 2009). Thus, an interview is a face-to-face or voice-to-voice conversation directed by a researcher to obtain relevant data, information, expressions, opinions and beliefs related to the research objectives.

Interviews help researchers gather enough information; they offer the opportunity for explanation, investigation, modification and clarification of the data in the interaction between the researcher and the interviewees (Gillham, 2005). Interviews have many advantages, including the generation of important and rich data that cannot be produced by other methods, allowing an opportunity to follow up incomplete or unclear data responses by asking further questions for clarification, modification, and to gain more in-depth data from participants (Gay & Airasian, 2000).

A semi-structured interview was selected for this study to allow interaction and access to information from the respondents, while keeping the conversation within the strict parameters of the research questions. The researcher developed the interview questions based on the research problem and then focused on the research questions in the ensuing conversation.

The semi-structured face-to-face interviews in this study were conducted with 12 Saudi mothers (given that fathers were only allowed visitation during specific hours) who responded to the invitation to be interviewed. These interviews were conducted by asking 15 questions (see Appendix O) to provide a better

understanding of stress and coping mechanisms of Saudi families. The questions focused on understanding how parents felt when they realised their child had a chronic illness, what emotions they experienced, how the family reacted to the news and how long it took their other child to accept the news of a sick brother or sister. Areas of concern to the parents were also explored. After interviewing 10 mothers, saturation level was reached, where all the finding's themes were similar. To insure that all themes, issues and information were addressed, two further interviews were conducted. These face-to-face interviews were conducted at a time convenient to the mothers, either when the child was sleeping or when the child was able to attend the ward playroom. No interviews were conducted at the bedside. These interviews were conducted in Arabic and were audio tape recorded. An official sworn translator translated these transcripts into English (see Appendix Q).

Face-to-face interviews with registered paediatric nurses were also conducted and saturation of information was reached after interviewing 15 nurses (Morse, 1995). After interviewing 12 nurses, saturation level was reached, where all the finding's themes were similar. To insure that all themes, issues and information were addressed, three further interviews were conducted. All the interviews were conducted in a meeting room on the ward. The researcher conducted the face-to-face interviews by asking 11 questions (see Appendix N) to obtain information on the nurses' objective observations of how they felt Saudi parents coped with having with having a chronically ill child. The nurses were requested to provide information on what they were offering to assist these parents to cope with caring for their chronically ill children. Additionally, information was gathered regarding whether the Saudi health care system offered any assistance to these families through the

hospital. These interviews were conducted in English and were audio tape recorded and transcribed by the researcher in English.

4.7.2 Content validity.

The face-to-face interviews were content validated by the same expert panel of Phase 1. The content of the Phase 2 interview and suggested questions were circulated to experts to rate the relevancy of the discussion content. The expert panel recommended expanding the interview questions. Additionally, the panel approved the interview questions, including the suggested questions for the parents and nurses' face-to-face interviews. One of the five mothers used to pilot the questionnaire also participated in piloting the interview questions.

4.7.3 Qualitative data collection.

Participants attended the semi-structured face-to-face interviews voluntarily and could withdraw at anytime during the interview. All interviewees (mothers and nurses) ($N=27$) were given a choice of interview language. Before the interview, all interviewees were handed a plain language statement describing the study, and had to sign the consent form (see Appendices I, J & K). All participants were assured that they would not be identified, and their responses were reported as group themes only. Nurses' interviews were identified using numbers, while mothers' interviews were identified using pseudonyms.

Permission was sought from the hospital to use a meeting room outside the ward in each hospital to conduct the face-to-face interviews to protect their anonymity. The nurses' interviews were held in English and the mothers' interviews were in Arabic. The length of the interviews on average was around 30 to 45 minutes. Four mothers refused to have the interview recorded, so the researcher took notes throughout the interview.

The mothers' interviews were transcribed verbatim into Arabic, then translated into English by a professional translator. The researcher is an experienced nurse, who has worked in paediatric wards and has undertaken a Communication and Counselling for Health Care Professionals Course in her postgraduate studies; she conducted all the interviews. If any of the participants became distressed during the interview, the researcher stopped the interview, and the interview was either be rescheduled or reconverted. The researcher was equipped and capable to handle distressed mothers, as she is an experienced paediatric nurse, who could if necessary, make referrals to counsellors or social workers. No participants become distressed during the interview.

4.7.4 Qualitative data analysis.

Analysis commenced after each interview to keep the participants' views and insights fresh and the researcher focused on the research problem. The recordings were transcribed and carefully revised to ensure that the transcription was accurate and had no missing points. All mothers' Arabic interviews were translated into English by a professional translation office in Jeddah. Following translation, the researcher, along with the professional translator, carefully revised and compared the translation with the original interview transcriptions to ensure that the translations were correct, and that meaning had not been lost or altered in the translation. The process of transcription for each interview took between one and two days' work, so that over the months, there was sufficient time to think about each interview transcript in detail. The transcription was made by playing back the audio tape recorded interviews several times, and from the notes taken during some interviews.

The face-to-face interviews were analysed and several themes were identified with regard to the nurses' and mothers' knowledge, and factors affecting the coping

mechanisms of families with chronically ill children. According to Minichiello, Aroni and Hays (2008), content analysis procedures are a suitable technique to identify themes emerging from analysis of interview transcripts. Data analyses were conducted using a content analysis technique to identify relevant responses and commonality in responses among the different interviews.

Through the analysis process, the researcher identified, coded and categorised the patterns that emerged from the data (Charmaz, 2006). Statements made by participants, considered relevant for the study, were compared. The common statements were used to generate themes that represented the perceptions of the group. The coding process was completed through the systematic identification and categorisation of participants' responses to the semi-structured interview questions, and the codes were grouped according to content using a combination of inductive and deductive reasoning, allowing identification of similarities between responses (Merriam, 2009). The coded statements were clustered into thematic categories. The thematic categories were then further reviewed and compared, yielding the overall themes representative of the different perceived elements central to the phenomenon for the participants. These thematic categories are presented as part of the findings. To support theme generation and an in-depth understanding of the participants' experiences and perceptions, textual data in the form of verbatim examples from the interview discussions were included in the report to highlight key themes.

NVivo 10® qualitative analysis software was used to assist in the coding and development of themes and patterns from the data. This software assists in the classification, sorting and arranging of information and tracks the frequency of occurrences across the data. According to Charmaz (2006), NVivo codes 'help us to

preserve participants' meanings of their views and actions in the coding itself" (p. 55). Finally, a comprehensive review and interpretation of the data provided the conclusions of the analyses, which represented the perceptions of the group as a whole and are presented according to the relevant associated research questions (Merriam, 2009).

4.7.5 Trustworthiness and rigour.

Rigour, reliability and trustworthiness include activities that increase the probability of credible findings being produced (Holloway & Wheeler, 2013). A study is said to be trustworthy if it is reliable and the findings are deemed accurate. Rigour is commonly applied to encourage researchers to question their assumptions and think deeply. According to Holloway and Wheeler (2013), quantitative researchers use rigour because of its appropriate place in specifying particular connections with measurement and objectivity. However in qualitative research, rigour is indicated by thoroughness and competence. It is useful in qualitative research for an accurately represented study that contributes to rigour (Speziale, Streubert & Carpenter, 2011; Strubert & Carpenter, 2011). Rigour is demonstrated through researchers' attention to and confirmation of information discovery (Speziale et al., 2011).

Although some qualitative researchers believe that rigour is a concept that has no place in qualitative research, it has been defined by other qualitative researchers as the means by which qualitative research shows integrity and competence (Holloway & Wheeler, 2002). Reliability in qualitative research refers to the consistency of the research instrument. It is also linked to replicability; that is, the extent to which the study is repeatable and produces the same results when the methodology is replicated in similar circumstances and conditions (Holloway &

Wheeler, 2002). As the researcher is the main instrument in qualitative research, the research can never be replicable: steps towards ensuring replicability used in this research included the same questions being used for each interview. The researcher's characteristics and background will influence the research. Trustworthiness in qualitative research means methodological soundness and adequacy. There are different terms that describe the process that leads to rigour in qualitative research. Operational techniques supporting a study's rigour include credibility, dependability, confirmability and fittingness (Churchill & Lacobicci, 2010; Holloway & Wheeler, 2013; Strubert & Carpenter, 2011).

Credibility can be defined as using measures to increase the chances of producing credible findings (Speziale et al., 2011). In other words, this refers to confidence in qualitative data and the interpretation of those data. Confirmability refers to the process that enables other researchers to follow and audit the research. This requires the researcher to be clear and objective in conducting, documenting, managing and reporting the research process. Through this process, the drawn conclusions can be traceable and confirmable (Speziale et al., 2011). Transferability is the likelihood that the findings from the research can be applied to a similar population, and how significant they are to others (Speziale et al., 2011). Finally, triangulation is a technique used by the researcher to strengthen the research's rigour by examining the subject under study from different perspectives. If the two perspectives employed give similar findings, it is assumed that the validity of those findings has been established. Further, triangulation employs comprehensive, multi-perspective views and procedures to reduce potential biases within the research design (Silverman, 2011).

In this research, rigour was achieved by undertaking the following: establishing and following the research methods; content validity through use of an expert panel; use of the same interview questions; sampling techniques to ensure a variety of different participants; audio tape recording of interviews, transcribed verbatim; transcripts checked with recording for accuracy; transcripts and analysis checked with supervisor for accuracy; use of NVivo; use of participants' comments for writing up the analysis; keeping an audit trail; and triangulating the data.

4.8 Ethical Considerations

According to Burns and Grove (2005), ethical research is important to generate sound knowledge for practice. This study was conducted according to fundamental ethical and human rights principles that were protected during the entire research process. These principles included self-determination, privacy, anonymity and confidentiality, and protection from discomfort and harm.

An ethics application was submitted and granted by the College Human Ethics Advisory Network (CHEAN) in RMIT University (BSEHAPP 33 – 11 KATOOA) (see Appendix A). Additionally, the Saudi Health and Medical Research Committee and the High Authority of the Nursing Department in the Saudi MOH granted their approval to conduct the study in Ministry hospitals (see Appendix B). Moreover, an approval letter from each of the Maternity and Children Hospital (MCH), King Abdul Aziz University Hospital (KAAH), and King Faisal Specialist Hospital and Research Centre (KFSH) was granted and attached to the application for ethics approval in Saudi Arabia (Appendix C, D & E).

4.8.1 Confidentiality and anonymity.

Participation in this study was voluntary. All individuals who participated in this study received verbal and written explanation through the plain language statement (in both English and Arabic) of the procedures involved and the benefits expected from the study. The plain language statement was also attached to the questionnaire. All respondents were asked to sign an informed consent form (provided in both English and Arabic) prior to the commencement of the interview. Participants were also advised that participation was voluntary and they were able to withdraw at any time during the interview if they so wished. Anonymity of participants and confidentiality of all the data were guaranteed during the process of data collection by removing any potentially identifying information. It was explained that all results would be reported only as group data, so that no individual could be identified. Participants' interview data through the quotations are identified by pseudonyms for mothers and numbers for nurses.

4.8.2 Data record keeping and security of research data.

Walsham (2006) notes it is imperative to the integrity of the study that all material collected for the research project is kept confidential. Therefore, consent forms, completed questionnaires, notes, data analysis notes and transcribed documents were kept in a locked filing cabinet at RMIT University. During the research process, all computers were password protected and only authorised people were able to access the research data. Files were saved and were able to be viewed only by the researchers; back-up files were placed on a password protected flash drive and the RMIT University drive, which was password protected, during the conduct of the study. All demographic information, that is, names and telephone numbers, were kept separately from all other data. Moreover, upon completion of the

research, labelled data and records will be stored in the research and data storage department area at the university for five years before being destroyed. All data will be shredded or erased five years post-completion of the study, as per RMIT guidelines (RMIT University protocol and guidelines; NHMRC, 2011).

4.9 Summary

A comprehensive picture of the research methodology was provided in this chapter to help understand how Saudi parents cope with chronically ill children in three main public hospitals in Jeddah region, Saudi Arabia. An explorative descriptive cross-sectional design was used to answer the research questions and to guide this research. Quantitative and qualitative data from semi-structured interviews were collected to determine the factors that lead to resilience in Saudi parents with chronically ill children. Data were collected in two phases. The first phase involved a survey questionnaire that elicited information on demographics, quality of life, self-efficacy and social support. Then, the second phase involved interviews with parents and nurses. In addition, this chapter described the study setting, the sampling strategy of the study, the instruments used for data collection, face-to-face interviews, validity and reliability, trustworthiness and rigour and the ethical considerations of the study. The findings from the analyses of the quantitative data will be presented in the Chapter 5, and then the analyses of the qualitative data will be presented in Chapter 6.

Chapter Five: Quantitative Statistical Analyses

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Chapter 5 : Quantitative Statistical Analysees

5.1 Introduction

The purpose of this study was to identify factors related to resilience among Saudi parents when faced with the adversities of chronically ill children, in three main public hospitals in the Jeddah region, Saudi Arabia. Three-hundred-and-fifty-eight questionnaires were distributed across the three hospitals and 122 were returned, with a response rate of 34 per cent. This chapter will describe the statistical analyses of the quantitative data from a convenience sample of 122 Saudi parents of chronically ill children in the three main public hospitals in the Jeddah region. The data were analysed using the SPSS Version 20.00 software.

The statistical analyses of the study were divided into two main sections whereby descriptive and inferential statistical analyses were conducted. The descriptive statistics involved measures of frequency, mean and standard deviation for each item of the questionnaire and the overall satisfaction scores of the subjects. The inferential statistical included the analysis of variance were used for comparisons between two variables. In addition, one-way ANOVA were used to identify comparisons between more than two variables. Finally, a classification model to measure resilience was used by examining stress and adversity and QOL.

5.2 Descriptive Statistics

A convenience sample of 122 (response rate 34 per cent) Saudi parents with chronically ill children from the three hospitals in Jeddah region in Saudi Arabia responded to the questionnaire. Twenty-four per cent of the participants responded from MCH, 43 per cent were from KAAH and 33 per cent were from KFSH&RC hospitals (see Table 5.1). The participants' level of resilience was examined in

relation to various independent variables. The first part comprised the demographic characteristics of the participants. These included the parent's gender, relationship to the chronically ill child, age, marital status, occupation, income and highest educational level. Information on the structure of the family and illness characteristics was provided by questions about the total number of children, and the age, gender and living arrangements of all their children, as well as identifying who of the children were healthy or sick, the child's chronic illness (type and diagnosis), duration of the child's chronic illness, time parents spent in caring activities for their sick child, time the family spent together, and whether family had received respite help. The second part included existing scales, such as the GSE (Schwarzer & Jerusalem, 1995), SSQ (Sarason et al., 1983) and QOL scale (Flanagan, 1982).

Table 5.1

Selected Hospitals of the Study (N=122)

Participants of the study	N	Per Cent
Maternity & Children Hospital (MCH)	30	24
King Abdul Aziz Hospital (KAAH)	52	43
King Faisal Specialist Hospital and Research Centre (KFSH&RC)	40	33

5.2.1 Demographic and group characteristics.

The demographic data collected through the survey consisted of the parents' gender, age, marital status, occupation, annual household income, level of education attained, number of children in the family, health status of the children, specific diagnosis or illness of the child, duration of the child's chronic illness, time spent

caring for the ill child, family time spent together, and whether the family received respite help and from whom.

As demonstrated in Table 5.2, 93 per cent were females and 92 per cent were mothers of chronically ill children. Thirteen per cent of the participants were less than 21 years of age, 43 per cent were 22 to 32 years, 30 per cent were 33 to 42 years, 12 per cent were 43 to 52 years and two per cent were aged above 53 years. Eighty-eight per cent of the participants were married, five per cent were widowed and seven per cent were divorced. More than half (56 per cent) of the participants were employed, while 44 per cent were unemployed. Participants' family annual income ranged as follows: 21 per cent received an annual income of 24,000 to 35,000 SR; 28 per cent received an annual income of 36,000 to 45,000 SR; 16 per cent received an annual income of 46,000 to 55,000 SR and 35 per cent received an annual income of 55,000 SR and above. The majority of participants had at least a secondary or technical level of education (39 per cent had a technical certificate, 26 per cent had a secondary school education, 27 per cent had a tertiary degree) (see Table 5.2).

Table 5.2

Demographic and Group Characteristics of the Study (N=122)

Participants of the study	N	Per Cent
<u>Gender:</u>		
Male	8	7
Female	114	93
<u>Relationship to the chronically ill child:</u>		
Mother	112	92
Father	8	7
Grand Parent	2	1
<u>Age groups:</u>		
Less than 21	16	13
22–32	53	43
33–42	37	30
43–52	14	12
Above 53	2	2
<u>Marital status:</u>		
Married	108	88
Widowed	6	5
Divorced	8	7
<u>Occupation:</u>		
Employed	68	56
Unemployed	54	44
<u>Family annual income:</u>		
SR (24,000–35,000)	26	21
SR (36,000–45,000)	34	28
SR (46,000–55,000)	19	16
SR (55,000 and above)	43	35
<u>Highest level of education:</u>		
Primary	9	8
Secondary	32	26
Technical	48	39
Tertiary	33	27

Note: Exchange rate: 1 SR = 0.34 AUD

5.2.2 Family structural information and illness characteristics.

Parents were asked detailed information about their family structure, the number of sick children in the family, the types of illnesses their children have and the duration of their children's illnesses. They were also requested to identify how much time they were spending with their immediate family, and they were asked whether they received respite help, and to identify the source of this respite help.

Table 5.3 below shows the responses of Saudi parents with chronically ill children. The majority of parents (71 per cent) reported having between one and six children. The majority of the participants in this study (77 per cent) indicated that they had only one child suffering from a chronic illness, whereas 23 per cent reported having two to five children suffering from a chronic illness.

Parents provided detailed information on their children's illnesses or conditions. The most common illness reported included: respiratory diseases (32 per cent) and diabetes (26 per cent), with reports of cancer (leukaemia, brain tumour) (16 per cent), blood disorders (anaemia, thalassemia) and cardiovascular diseases (14 per cent), bone and joint conditions (12 per cent), neurological conditions (11 per cent), and kidney and urologic conditions (9 per cent).

Parents provided information about the age of the child at the onset of illness, amount of time spent on caring for the child, and the daily activities of the children with chronic illnesses. All illnesses were long term and required significant care. Nearly half of the children (48 per cent) had an age of onset of one to two years, and 22 per cent of the children had chronic illnesses from birth. Almost half of the children (43 per cent) required continuous care, yet the majority of the parents (75 per cent) indicated that they spent time daily with their immediate family.

Parents were also asked to provide information on the sources of respite help they received. Nearly 60 per cent of the participants stated that they received respite help from family and or friends, 25 per cent reported receiving help from multiple sources (including not only family and friends, but also government associations and the hospital). Eighteen per cent of the participants indicated that they were not receiving any respite help (see Table 5.3).

Table 5.3

Family Structural Information and Illness Characteristics of the Study (N=122)

Participants of the study	N	Per Cent
<u>Number of children:</u>		
1	35	29
2	30	24
3	22	18
4	21	17
5	7	6
6	7	6
<u>Child's Chronic Condition:</u>		
Neurological condition	13	11
Blood diseases (Anaemia, Thalassemia)	17	14
Cancer (Leukaemia, Brain Tumour)	20	16
Respiratory diseases	39	32
Cardiovascular diseases	17	14
Diabetes diseases	32	26
Bone and Joint conditions	15	12
Kidney and Urologic conditions	11	9
<u>Duration of child's chronic illness:</u>		
From birth	27	22
1-2 years	59	48
3-4 years	23	19
Above 5 years	13	11
<u>Time spent each day in caring activities:</u>		
Less than 1 hour	1	1
2-3 hours	13	11
4-5 hours	29	24
More than 6 hours	26	21
Continuous care	53	43
<u>Immediate family spent time together:</u>		
None	1	1
1-2 hours/day	1	1
3-4 hours/day	4	3
5 and more hours/day	14	11
Daily	92	75
Once a week	0	0
2-3 times a week	8	7
Monthly	2	2
<u>Respite help:</u>		
Family	21	17
Friends	1	1
Hospital	1	1
Government association	2	6
Family and friends	50	42
All	31	15
No help	18	18
<u>Number of sick children in each family:</u>		
1	94	77
2	22	18
3	5	4
5	1	1

5.2.3 Children—structural information.

The demographic survey requested information on the number of children in each family, the children's ages, their gender, whether they were living at home with their parents and the health status of their children. The distribution of ages, along with basic descriptive statistics for the overall sample, is shown in Figure 5.1.

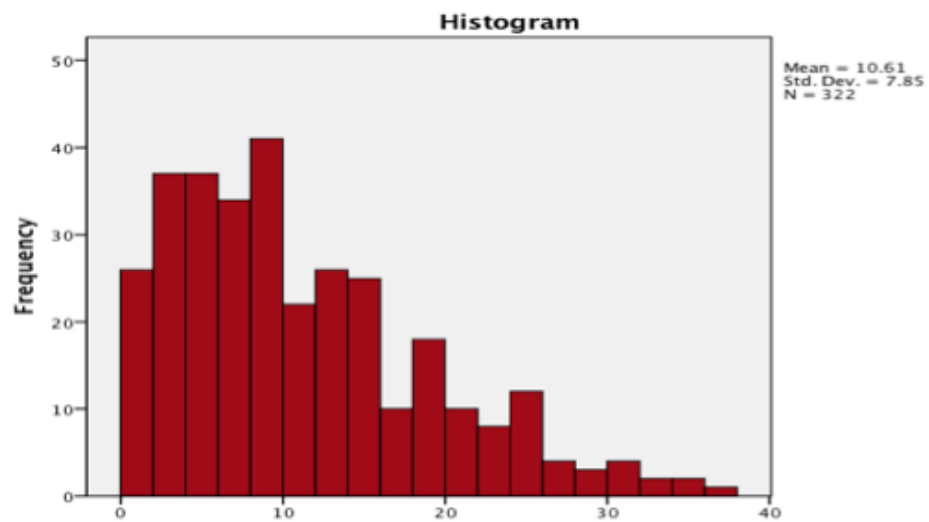


Figure 5.1: Frequency distribution of children's age.

Table 5.4 below shows the responses of Saudi parents regarding the gender of their children, if their children lived with them, and the health status of their children. Gender was evenly distributed (52 per cent boys, 48 per cent girls), and the majority of the parents (90 per cent) reported that their children were living with them. Among those who reported that their children were not living with them (10 per cent), this was reportedly because some of the children were older and married, living with their own families. Parents also provided information on the health status of their children, which for the most part, was evenly split between healthy and sick children.

Table 5.4

Children—Structural Information (N=322)

Participants of the study	N	Per Cent
<u>Gender:</u>		
Boy	168	52
Girl	154	48
<u>Living arrangements:</u>		
Yes	289	90
No	33	10
<u>Health:</u>		
Healthy	164	51
Sick	158	49

5.3 Research Instruments

Data were collected using three instruments to assess the parents' self-efficacy, social support and QOL, three reliable and valid instruments were used. These instruments were the GSE, the SSQ and the QOL scale. These instruments had Likert-type response scales that were used to enable the researcher to quantify the variables being measured for data analysis. More explanations of each scale will be provided below.

5.3.1 The general self-efficacy scale.

The individual item responses for the GSE are presented in Table 5.5 below. The GSE scores will also be used later in this chapter in the analysis involving identifying the relationship between self-efficacy and resilience. Dividing the value of the mean responses into the four categories (1=not at all true, 2=hardly true, 3=moderately true, 4=exactly true) using the mean score differentiations, three terms demonstrated an 'exactly true' mean score, which included 'I can solve most problems if I invest the necessary effort', 'I can remain calm when facing difficulties' and 'I can usually handle whatever comes my way'. However, most

subjects demonstrated a 'moderately true' score. Also, it was found that the overall combined mean was 3.25, which reflects a 'moderately true' mean response. In addition, the total GSE scale scores demonstrated a mean (*M*) of 32.52 for the group of 122 subjects, with a standard deviation (*SD*) of 4.05. Compared to what was published by Schwarzer and Jerusalem (1995), a correlation of at least 0.80 is suggested for at least one type of reliability as evidence; however, standards range from 0.5 to 0.9 depending on the intended use and context for the instrument.

The General Self-Efficacy Scale Results

	Not at all true		Hardly true		Moderately true		Exactly true		Mean	Std. Deviation	Ranking	Mode
	Per cent	N	Per cent	N	Per cent	N	Per cent	N				
I can always manage to solve difficult problems if I try hard enough.	1.6	2	3.3	4	69.7	85	25.4	31	3.19	.565	6	Moderately true
If someone opposes me, I can find the means and ways to get what I want.	1.6	2	2.5	3	70.5	86	25.4	31	3.20	.555	5	Moderately true
It is easy for me to stick to my aims and accomplish my goals.	1.6	2	4.9	6	72.1	88	21.3	26	3.13	.560	9	Moderately true
I am confident that I could deal efficiently with unexpected events.	-	-	4.9	6	73.8	90	21.3	26	3.16	.487	8	Moderately true
Thanks to my resourcefulness, I know how to handle unforeseen situations.	-	-	4.9	6	69.7	85	25.4	31	3.20	.513	5	Moderately true
I can solve most problems if I invest the necessary effort.	.8	1	3.3	4	27.9	34	68.0	83	3.63	.592	1	Exactly true
I can remain calm when facing difficulties because I can rely on my coping abilities.	4.1	5	6.6	8	46.7	57	42.6	52	3.28	.763	3	Exactly true
When I am confronted with a problem, I can usually find several solutions.	-	-	8.2	10	69.7	85	22.1	27	3.14	.535	7	Moderately true
If I am in trouble, I can usually think of a solution.	.8	1	5.7	7	60.7	74	32.8	40	3.25	.597	4	Moderately true
I can usually handle whatever comes my way.	1.6	2	6.6	8	49.2	60	42.6	52	3.33	.673	2	Exactly true
	Combined Mean (3.25 = Moderately true)											

5.3.2 The Social support questionnaire.

Results from the SSQ were also provided by individual item scores and by total SSQ score. The individual item scores were divided into six categories (1= strongly disagree, 2= disagree, 3= slightly disagree, 4= slightly agree, 5= agree, 6= strongly agree). From Table 5.6 below, the results show eight items that demonstrated a mean response score in the 'strongly agree' range and four terms that demonstrated a mean response score in the 'agree' range. The overall combined mean was 5.31, which means that the subjects 'strongly agreed', representing a high social support result. In addition, descriptive statistics for the SSQ score demonstrated $M = 63.66$, ($SD = 11.665$) for the group of 122 participants, with a minimum score of 12 and a maximum score of 73. Compared to what was published by Sarason et al. (1983), the overall satisfaction score is calculated by the means of the 27 satisfaction scores.

Table 5.6

The Social Support Questionnaire Results

	Strongly disagree		Disagree		Slightly disagree		Slightly agree		Agree		Strongly agree		Mean	SD	Std.	Ranking
	Per cent	N	Per cent	N	Per cent	N	Per cent	N	Per cent	N	Per cent	N				
There is a special person who is around when you are in need.	1.6	2	-	-	.8	1	10.7	13	13.1	16	73.8	90	5.55	.919	Strongly agree	5
There is a special person with whom you can share joys and sorrows.	.8	1	1.6	2	1.6	2	7.4	9	12.3	15	76.2	93	5.57	.926	Strongly agree	2
Your family really tries to help you.	.8	1	.8	1	4.1	5	4.9	6	11.5	14	77.9	95	5.59	.925	Strongly agree	1
You get the emotional help and support you need from your family.	1.6	2	2.5	3	.8	1	5.7	7	12.3	15	77.0	94	5.56	1.021	Strongly agree	4
You have a special person who is a real source of comfort to you.	.8	1	.8	1	3.3	4	9.0	11	13.1	16	73.0	89	5.52	.947	Strongly agree	6
Your friends really try to help you.	5.7	7	4.9	6	.8	1	19.7	24	19.7	24	49.2	60	4.90	1.445	Agree	11
You can count on your friends when things go wrong.	5.7	7	5.7	7	5.7	7	16.4	20	19.7	24	46.7	57	4.79	1.506	Agree	12
You can really talk about your problems with your family.	3.3	4	2.5	3	3.3	4	7.4	9	15.6	19	68.0	83	5.34	1.237	Strongly agree	8
You have friends with whom you can share your joys and sorrows.	5.7	7	5.7	7	3.3	4	11.5	14	20.5	25	53.3	65	4.95	1.493	Agree	9
There is a special person in your life who cares about your feelings.	.8	1	1.6	2	1.6	2	8.2	10	11.5	14	76.2	93	5.57	.936	Strongly agree	3
Your family is willing to help you make decisions.	2.5	3	1.6	2	3.3	4	8.2	10	13.1	16	71.3	87	5.42	1.142	Strongly agree	7
You can talk about your problems with your friends.	6.6	8	4.9	6	4.1	5	13.9	17	18.0	22	52.4	64	4.91	1.543	Agree	10
Combined Mean (5.31 = Strongly agree)																

5.3.3 The Quality of life scale.

For evaluating the scale results, the QOL scale scores were divided by value into seven categories (1=terrible, 2=unhappy, 3=mostly dissatisfied, 4=mixed, 5=mostly satisfied, 6=pleased, 7=delighted). The terms were ranked according to their means, which indicated: (a) that marital comforts, such as home, food, conveniences, and financial security were ranked as first; (b) socialising, such as meeting other people, doing things, going to parties, was ranked second; (c) health, such as being physically fit and vigorous was ranked third; (d) health, such as being physically fit and vigorous was ranked fourth; and (e) the lowest rank was associated with the item of ‘participating in organisations and public affairs’ (see Table 5.7).

In addition, the overall QOL scores were calculated by summing the results of each item. The overall combined mean score for the group of study participants was 95.49 ($SD = 12.07$). Flanagan (1982) has reported similar reliability estimates for the 16-item scale. The overall QOL score is used later in the analysis to reveal group differences in QOL to define resilience.

Table 5.7

The Quality of Life Scale Results

	Strongly disagree		Disagree		Slightly disagree		Slightly agree		Agree		Strongly agree		Mean	SD	Std.	Ranking
	Per cent	N	Per cent	N	Per cent	N	Per cent	N	Per cent	N	Per cent	N				
There is a special person who is around when you are in need.	1.6	2	-	-	.8	1	10.7	13	13.1	16	73.8	90	5.55	.919	Strongly agree	5
There is a special person with whom you can share joys and sorrows.	.8	1	1.6	2	1.6	2	7.4	9	12.3	15	76.2	93	5.57	.926	Strongly agree	2
Your family really tries to help you.	.8	1	.8	1	4.1	5	4.9	6	11.5	14	77.9	95	5.59	.925	Strongly agree	1
You get the emotional help and support you need from your family.	1.6	2	2.5	3	.8	1	5.7	7	12.3	15	77.0	94	5.56	1.021	Strongly agree	4
You have a special person who is a real source of comfort to you.	.8	1	.8	1	3.3	4	9.0	11	13.1	16	73.0	89	5.52	.947	Strongly agree	6
Your friends really try to help you.	5.7	7	4.9	6	.8	1	19.7	24	19.7	24	49.2	60	4.90	1.445	Agree	11
You can count on your friends when things go wrong.	5.7	7	5.7	7	5.7	7	16.4	20	19.7	24	46.7	57	4.79	1.506	Agree	12
You can really talk about your problems with your family.	3.3	4	2.5	3	3.3	4	7.4	9	15.6	19	68.0	83	5.34	1.237	Strongly agree	8
You have friends with whom you can share your joys and sorrows.	5.7	7	5.7	7	3.3	4	11.5	14	20.5	25	53.3	65	4.95	1.493	Agree	9
There is a special person in your life who cares about your feelings.	.8	1	1.6	2	1.6	2	8.2	10	11.5	14	76.2	93	5.57	.936	Strongly agree	3
Your family is willing to help you make decisions.	2.5	3	1.6	2	3.3	4	8.2	10	13.1	16	71.3	87	5.42	1.142	Strongly agree	7
You can talk about your problems with your friends.	6.6	8	4.9	6	4.1	5	13.9	17	18.0	22	52.4	64	4.91	1.543	Agree	10
Combined Mean (5.31 = Strongly agree)																

5.4 Correlations

Correlation statistics were calculated to reveal correlations among social support, QOL, and general self-efficacy. Table 5.8 below shows the correlations among QOL, GSE, SSQ and stress and adversity, duration of child's chronic illness, family time spent in caring activity, and immediate family time spent together.

There was found to be a significant correlation between QOL score and GSE ($p < .001$), between QOL and SSQ ($p < .001$), between QOL and stress and adversity ($p = .02$), between GSE and SSQ ($p < .001$), and between stress and adversity and family time in caring activities ($p < .001$). There is only one significant correlation related to duration of child's chronic illness, which was with stress and adversity. This was not related to QOL, GSE or SSQ. SSQ and immediate family time spent together did not correlate with any of the variables. In addition, a nearly significant result or trend was found between GSE and stress and adversity ($p = .06$) (see Table 5.8).

Table 5.8

Correlations QOL, GSE, SSQ, Stress & Adversity, Duration of Child's Illness, Family Time Spent in Caring Activity, and Immediate Family Spent Time Together

		Total QOL	Total GSE	Total SSQ	Total Stress & Adversity	Duration of child's chronic illness	Family time spent in caring activities for the sick child	Immediate family spent time together
Quality of Life Scale (QOL)	<i>r</i>	1	.46**	.71**	.21*	<.01	-.06	-.01
	<i>p</i>		< .001	< .001	.02	.95	.50	.95
Total General Self-Efficacy Scale (GSE)	<i>r</i>		1	.41**	.17	.11	-.11	.01
	<i>p</i>			< .001	.06	.25	.24	.89
Total Social Support Questionnaire (SSQ)	<i>r</i>			1	.03	-.01	-.03	.11
	<i>p</i>				.76	.91	.76	.24
Total Stress & Adversity	<i>r</i>				1	.56**	.46**	-.04
	<i>p</i>					< .001	< .001	.67
Duration of child's chronic illness	<i>r</i>					1	-.029	.10
	<i>p</i>						.75	.40
Family time spent in caring activities for the sick child	<i>r</i>						1	.01
	<i>p</i>							.95
Immediate family spent time together	<i>r</i>							1
	<i>p</i>							

Note: N= 122

** . Correlation is significant at the .01 level

* . Correlation is significant at the .05 level

5.5 Inferential Statistics

Inferential statistics, whereby comparisons between two variables and one-way ANOVA, were used to identify comparisons between more than two variables, and a classification model was used by examining stress and adversity and QOL.

5.5.1 Description of analyses and classification model of resilience.

As described in Chapter 4, this approach to operationalising resilience consisted of first obtaining a measure that represented the overall level of stress and adversity for each participant. While the research instruments used in this study did not directly measure stress and adversity, eight individual questions from the demographic questionnaire related to stress and adversity representing the following variables were selected as measures of stress and adversity: occupation, income, education, number of sick children with a chronic illness in each family, type of child's chronic illness, duration of child's chronic illness, the time parents spent in caring activities for their sick child, and whether the family received respite help. The scores for each demographic item were added together to obtain a final total single score that indicated the level of stress and adversity of Saudi parents in this sample. The higher the score, the higher the level of stress and adversity experienced by the parents.

In the next stage, a score for adaptation to that stress and adversity from the QOL scale was obtained. The score for QOL and the total stress and adversity score were used to indicate the level of QOL and stress and adversity experienced by each parent, which was then used to classify participants into categorical stress and QOL groups. These results were then used to classify participants into different resilience groups. Scores on

the individual scores obtained from each participant on stress and adversity were ranked from highest to lowest.

Two statistical criteria for classifying participants into stress and QOL groups were used. Stress groups were created based on both median splits and quartile splits. The same process was undertaken for the QOL scores, where QOL groups were obtained from both median splits and quartile splits.

To create resilience groups, every combination of the stress and QOL life groups was cross-tabulated, with four labelled groups in each cross-tabulation. These four possible combinations in each cross-tabulation were labelled in the following way: 1=resilience (high stress, high QOL); 2=low QOL, high stress; 3=at risk (low QOL, low stress); and 4=high QOL, low stress. All possible combinations of the cross-tabulation of stress and adversity groups were examined, with the goal of identifying one that had an adequate sample size in each resilience group.

Subsequently, the last stage produced a classification model of resilience, which was based on the principles of the full classification model described by Masten and Reed (2002), and similar to that used by Luthar (1991) and Masten et al. (1999). This model was then applied to this study. It is important to note that this approach to operationalising resilience is not something being undertaken for the first time in this research study. Other researchers (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006) have used this approach in extracting a classification for resilience. According to this approach, participants were classified into four resilience groups, based on combinations of risks

or levels of stress (high or low) and levels of competence or adaptation (positive or negative). The inclusion of both high risk and low risk (according to high or low stress) participants allows for comparison of high risk participants who do well and adapt and move on with their lives (i.e., resilient) with those who do not, as well as a comparison of resilient participants with low risk, positively adapted participants. Some studies have found that, regardless of risk level, individuals demonstrating positive adaptation exhibit few differences in competencies (e.g., Masten et al., 1999). In contrast, others have found that resilient individuals do worse on some indicators, such as they exhibit symptoms of depression and anxiety, than their competent, low risk peers (e.g., Luthar, 1991). Interestingly, studies that have used the full classification model have commonly found that very few individuals fit the classification of low risk and negative adaptation (Luthar, 1991; Masten et al., 1999). This has been referred to by Masten et al. (1999) as the 'empty cell phenomenon'.

In this research, a total of 57 participants were classified into four groups based on stress and adversity (high or low) and QOL (high or low). Nineteen of the participants had been identified with high stress and adversity levels and high QOL. These were classified as the resilient group and they constituted 16 per cent of the total sample. Eight of the participants (7 per cent) with low stress and adversity and high QOL levels were doing well and were able to deal with their lives. Fifteen of the participants (12 per cent) had high stress levels and low QOL. This is not surprising, and is to be expected; 15 of the participants (12 per cent) had low stress and adversity and low QOL. This group is of great concern, as they reflect people with very poor coping

skills. Figure 5.2 below illustrates the division of these groupings according to stress and adversity levels and QOL category, and determines the label of resilience provided to these groups.

Stress & Adversity		
QOL	Low	High
High	Low Stress & Adversity High QOL (8 participants)	High Stress & Adversity High QOL = Resilience (19 participants)
Low	Low Stress & Adversity Low QOL (15 participants)	High Stress & Adversity Low QOL (15 participants)

Figure 5.2: Classification of groups based on high and low stress & adversity and QOL.

The total scores for GSE and SSQ were obtained and analysed to determine whether they were related to resilience. The SSQ was divided into two sub-scales: social support provided by family and special persons, and social support provided by friends. The SSQ and the four resilience groups were examined graphically and visible differences were noted in the graphs. The resilient group (high QOL—high stress and adversity) demonstrated the highest level of social support (as measured by the SSQ score), with similar levels evident to the high QOL—low stress and adversity group (See

Table 5.9, Figure 5.3). Visible differences were noted between the groups demonstrating high social support scores and the low QOL—high stress and adversity and low QOL—low stress and adversity groups, who demonstrated significantly lower levels of social support ($p < .001$), as evident in the descriptive and ANOVA analysis results provided in Tables 5.9 and 5.10 below. Although there was a significant difference in social support among the four groups (social support family and special person, and social support friends) by ANOVA, the results were similar when visualised in the graphs.

Post Hoc tests using a Tukey test were performed to follow up on these findings. Aligning with the previous conclusions, the resilient group demonstrated significant differences in GSE and SSQ scores compared with the low QOL—high stress group and the low QOL—low stress group, while demonstrating a similar level of general self-efficacy and social support as the high QOL—low stress group (see Table 5.11 below).

In terms of GSE, similar to the results for SSQ, the resilient group (high QOL—high stress) demonstrated significantly higher mean scores for self-efficacy (GSE), similar to the scores of the high QOL—low stress group (see Table 5.9, Figure 5.3 and Figure 5.4 below). These mean values were significantly greater than those of the less resilient low QOL—high stress, and low QOL—low stress groups ($p < .001$). Combined, these results demonstrated a significant relationship between self-efficacy beliefs and social support with resilience.

Table 5.9

Descriptive Statistics for GSE and SSQ by QOL–Stress Group

		95 Per Cent Confidence Interval for Mean					
		N	Mean	Std. Deviation	Std. Error	Lower Bound	Upper Bound
Total General	Resilient	19	35.05	3.100	.711	33.56	36.55
Self-Efficacy Scale	Low QOL High Stress	15	30.07	4.079	1.053	27.81	32.33
	Low QOL Low Stress	15	31.07	3.195	.825	29.30	32.84
	High QOL Low Stress	8	32.50	3.207	1.134	29.82	35.18
	Total	57	32.33	3.925	.520	31.29	33.37
Total Social	Resilient	19	69.53	3.702	.849	67.74	71.31
Support Questionnaire	Low QOL High Stress	15	51.53	17.936	4.631	41.60	61.47
	Low QOL Low Stress	15	56.47	12.415	3.205	49.59	63.34
	High QOL Low Stress	8	71.63	1.506	.532	70.37	72.88
	Total	57	61.65	13.911	1.843	57.96	65.34

Table 5.10

ANOVA Results for GSE and SSQ by QOL-Stress Groups

		Sum of Squares	df	Mean Square	F	Sig.
Total General	Between Groups	241.853	3	80.618	6.882	.001
Self-Efficacy Scale	Within Groups	620.814	53	11.713		
	Total	862.667	56			
Total Social	Between Groups	3912.904	3	1304.301	9.984	.000
Support Questionnaire	Within Groups	6924.079	53	130.643		
	Total	10836.982	56			

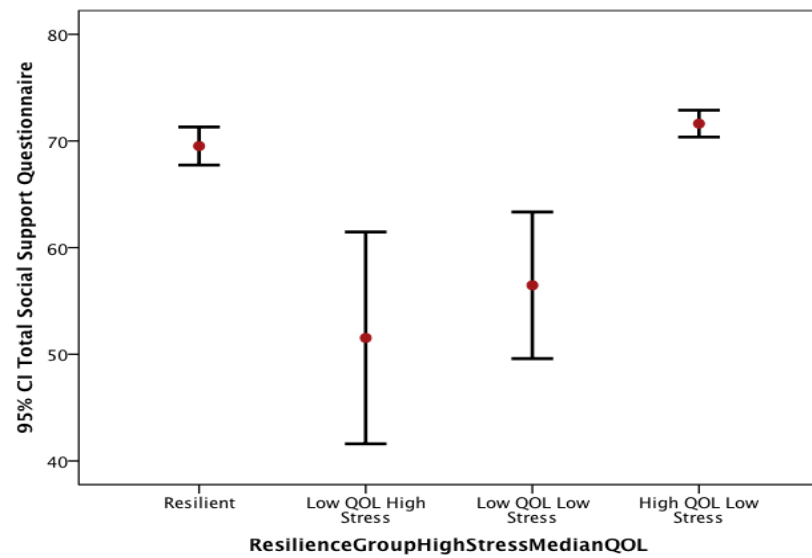


Figure 5.3: Graph of total SSQ v. QOL-stress groups.

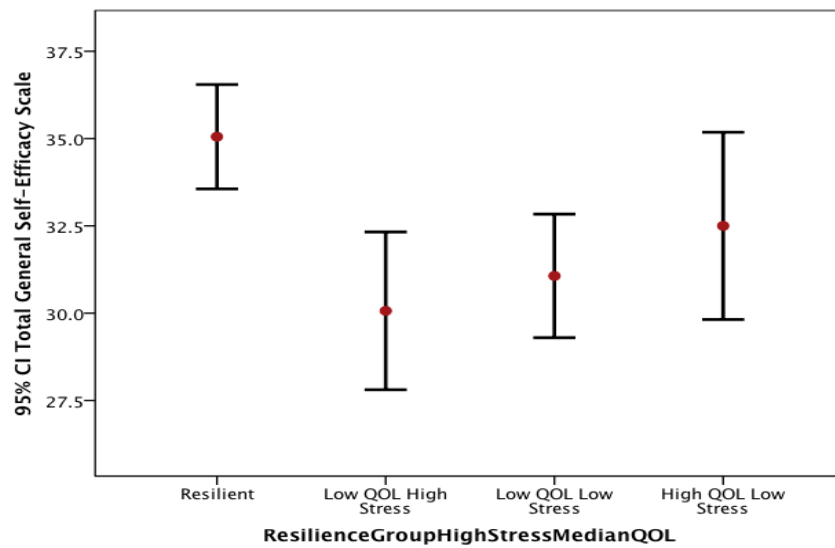


Figure 5.4. Graph of total GSE score v. QOL-stress groups.

Table 5.11

Multiple Comparisons using Tukey Test

Dependent Variable			Mean Difference		
	(I) Resilience Group	(J) Resilience Group	(I-J)	Std. Error	Sig.
Total General Self-Efficacy Scale	Resilient	Low QOL High Stress	4.986*	1.182	.001
		Low QOL Low Stress	3.986*	1.182	.007
		High QOL Low Stress	2.553	1.442	.299
	Low QOL High Stress	Low QOL Low Stress	-1.000	1.250	.854
		High QOL Low Stress	-2.433	1.498	.374
	Low QOL Low Stress	High QOL Low Stress	-1.433	1.498	.774
Total Social Support Questionnaire	Resilient	Low QOL High Stress	17.993*	3.948	.000
		Low QOL Low Stress	13.060*	3.948	.009
		High QOL Low Stress	-2.099	4.817	.972
	Low QOL High Stress	Low QOL Low Stress	-4.933	4.174	.641
		High QOL Low Stress	-20.092*	5.004	.001
	Low QOL Low Stress	High QOL Low Stress	-15.158*	5.004	.019

* The mean difference is significant at the 0.05 level

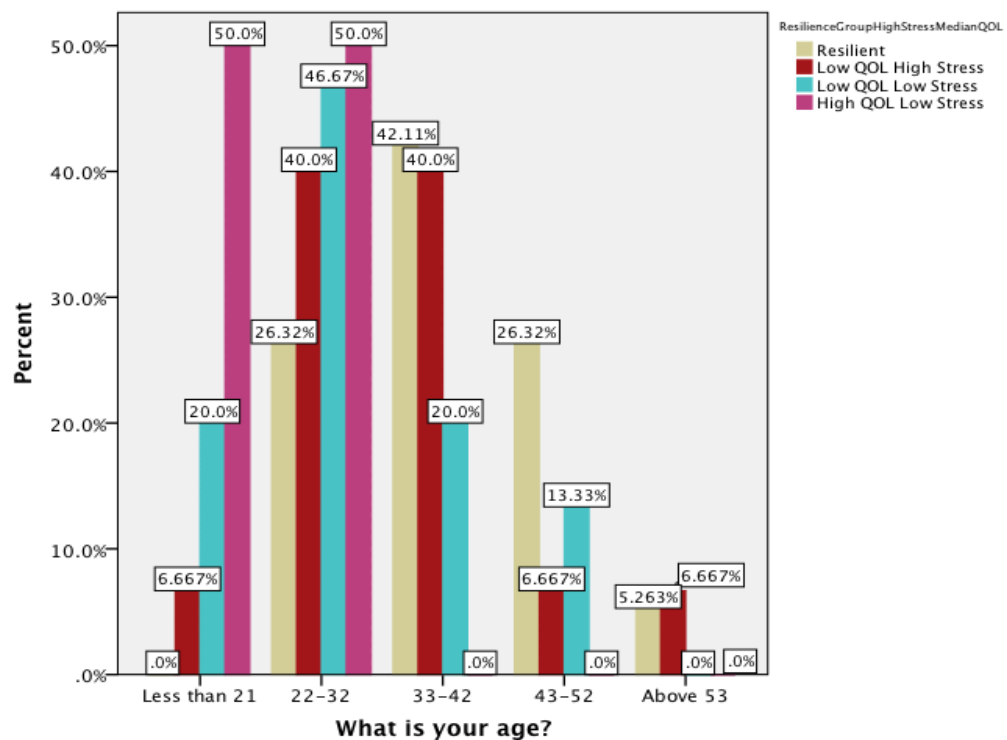
5.5.2 Parental age variable.

Comparing these results against parental age using a cross-tabulation, the study findings indicated a significant relationship with age, revealing that resilient parents tended to be older, [$\chi^2 (3, N = 57) = 16.80, (p = .001)$] (see Table 5.12, Figure 5.5).

Table 5.12

Cross-tabulations of QOL-Stress Groups and Age

		What is your age?					Total
		< 21	22-32	33-42	43-52	> 53	
Resilient	Count	0	5	8	5	1	19
	Per Cent within Resilient Group	0.0%	26.3%	42.1%	26.3%	5.3%	100.0%
Low QOL	Count	1	6	6	1	1	15
High Stress	Per Cent within Resilient Group	6.7%	40.0%	40.0%	6.7%	6.7%	100.0%
Low QOL	Count	3	7	3	2	0	15
Low Stress	Per Cent within Resilient Group	20.0%	46.7%	20.0%	13.3%	0.0%	100.0%
High QOL	Count	4	4	0	0	0	8
Low Stress	Per Cent within Resilient Group	50.0%	50.0%	0.0%	0.0%	0.0%	100.0%
Total	Count	8	22	17	8	2	57
	Per Cent within Resilient Group	14.0 %	38.6 %	29.8 %	14.0%	3.5%	100.0%
Chi-Square		16.796					
Df		3					
Asymp. Sig. (p)		.001					

*Figure 5.5. Cross-tabulations of QOL-stress groups and age.*

Therefore, these results indicated that the resilient parents of chronically ill children in this study were older and had significantly higher levels of general self-efficacy (as measured by the GSE scale) and social support (as measured by the SSQ), including both high levels of support from family and special person, and friends.

5.6 Summary

This chapter presented the statistical descriptive and inferential results of a study concerning the resilience of Saudi families with chronically ill children in three main public hospitals in the Jeddah region, in Saudi Arabia. This analysis section was divided into two main parts: the first part presented the descriptive statistics (such as measures of frequency, percentage, means and standard deviations for each item of the questionnaire and the overall satisfaction scores of the subjects). The second section of the analysis included inferential statistics, whereby ANOVA were used to identify comparisons between variables and resilience among participants, and a resilience classification model was used by examining stress and adversity and QOL.

The results of the quantitative statistical analyses provided significant correlations between QOL score and GSE, between QOL and SSQ, between QOL and stress and adversity, between GSE and SSQ, between stress and adversity and duration of child's illness, and between stress and adversity and family time spent in caring activities. In addition, a nearly significant result was found between GSE and stress and adversity.

Total scores for GSE and SSQ were investigated in relation to resilience. The resilient group (high QOL–high stress and adversity) demonstrated the highest levels of

social support, with similar levels evident to the high QOL–low stress and adversity group. Visible differences were noted between these groups and the low QOL–high stress and adversity and low QOL–low stress and adversity groups, which demonstrated significantly lower levels of social support ($p < .001$). Results of the analysis of GSE in relation to resilience were similar. The resilient group (high QOL–high stress and adversity) demonstrated significantly higher mean scores on self-efficacy (GSE), similar to the scores of the high QOL–low stress and adversity group. These mean values were significantly greater than those of the less resilient low QOL–high stress and adversity, and low QOL–low stress and adversity groups ($p < .001$). Using a Post Hoc Tukey test, the resilient group demonstrated significant differences in GSE and SSQ scores compared with the low QOL–high stress and adversity group and the low QOL–low stress and adversity group, while demonstrating a similar level of GSE and SSQ as the high QOL–low stress and adversity group. These results demonstrate the significant relationships between self-efficacy beliefs and social support and resilience.

In addition, upon comparing these results against parental age using a cross-tabulation (χ^2 test), the study results indicated a significant relationship with age variable, revealing that resilient parents tended to be older ($p = .001$). Overall, the analysis supported the model suggesting that resilience is related to age as well as social support and general self-efficacy. Chapter 6 will present the findings from the semi-structured interviews with Saudi mothers of chronically ill children and registered paediatric nurses.

Chapter Six: Qualitative Analyses

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Chapter 6 : Qualitative Analyses

6.1 Introduction

This chapter presents the analysis of the face-to-face interview responses. The analysis was conducted on the qualitative data obtained from the responses of 27 participants (15 nurses and 12 mothers) to the open-ended, semi-structured interview questions. Statements made by the participants relevant to the research questions were considered reflective of their perceptions and experiences (Moustakas, 1994). A qualitative process of coding and thematising (Creswell, 2009; Merriam, 2009) was used to analyse the statements, from which several themes were identified with regard to the nurses' and parents' knowledge and factors affecting the coping mechanisms of families with chronically ill children.

The data were analysed separately to reveal common responses and differences between the nurse participants and the mothers. The results are presented in two groups: nurses' interview findings and mothers' interview findings. Following the data analyses, findings for each sub-set were compared and integrated for discussion.

6.2 Overview of Analysis

Participants were asked if they would be willing to participate in the face-to-face interview, and provide their contact details accordingly. Face-to-face interviews, 15 paediatric nurses and 12 mothers, were conducted from MCH, KAAH and KFSH&RC hospitals paediatric units in the Jeddah region in Saudi Arabia. The aim of the interviews was to examine the perceptions and attitudes of the parents and nurses in

relation to parent and family stress in coping with a chronically ill child. The interviews were conducted to understand what support systems are in place to assist families in coping with the difficulties they face by having a chronically ill child.

Data analyses were conducted using a content analysis technique to identify relevant responses and commonality among the different interviews. The coding process was completed through the systematic identification and categorisation of participants' responses to the open-ended semi-structured interview questions, and the codes were grouped accordingly, using a combination of inductive and deductive reasoning, allowing for the identification of similarities among responses (Merriam, 2009). Through the analysis process, the researcher identifies, codes and categorises the patterns that emerge from the data (Patton, 1990). The responses were grouped into thematic categories based on the frequency of each element being mentioned in the interviews. The thematic categories were then further reviewed and compared, yielding the overall themes representative of the different perceived elements central to the phenomenon for the group of participants. Statements made by participants, which are essential to the participants' experience and perceptions (Moustakas, 1994) and are considered relevant to the study, are tracked and compared through a process of coding and analysis (Creswell, 2009). The common statements were used to generate themes that represent the perceptions of the group. The coded statements are grouped, or clustered, into thematic categories.

These thematic categories are presented as part of the findings. To support theme generation and in-depth understanding of the experiences and perceptions of the

participants, textual data in the form of verbatim examples from the interview discussions are included in the report to highlight the key common responses (themes). This then provides an in-depth understanding of the themes and allows for a more vivid portrayal of participants' experiences and perceptions (Creswell, 2009). NVivo 10® qualitative analysis software was used during the process of coding and development of themes. NVivo software provided an organised workspace to manage the data. The data from the nurses will be presented first.

6.3 Nurses' Demographic and Personal Characteristics

Fifteen paediatric nurses were interviewed. All interviewees were registered nurses from the three public hospitals in the Jeddah region. The interviewees had various qualifications; the majority had a Diploma of Nursing ($N=10$) and only five had higher qualifications, such as a bachelor degree or a postgraduate degree in nursing science. The majority were female and they all had different lengths of experience in nursing. Three of the participants had less than 5 years of experience, five participants had 5 to 7 years of experience, four participants had eight to 10 years of experience, two participants had 20 to 22 years of experience, while one had over 40 years of experience. Table 6.1 provides the demographic information for the 15 nurse interviewees, including their qualifications, marital status and experience.

Table 6.1

Demographics Information for the Nurse Interviewees

The Variable		<i>N</i> (15)	Per Cent
Education	Diploma of Nursing	10	67
	Bachelor of Nursing	3	20
	Master of Nursing	2	13
Marital Status	Married	11	73
	Single	4	27
Years of Experience	Less than 5 years	3	20
	5–7 years	5	33
	8–10 years	4	27
	20–22 years	2	13
	40 years and over	1	7

6.3.1 Nurses' interview findings.

To assist in addressing research questions three to five, the study employed a qualitative methodology to analyse interviews with 15 registered paediatric nurses. From these interviews, several categories were revealed; those which related to support are illustrated in Table 6.2. The results support five thematic categories, which included Saudi health care system support for families, hospital provided support for families, home health support for families, role of the paediatric nurse in supporting families, and factors affecting family stress and coping.

Table 6.2

Thematic Categories and Themes Revealed from Analysis of Interview Data

Thematic Category	Themes Included
Saudi Health care System Support for families	<ul style="list-style-type: none"> • Support for home care • Provide Free health care • Provide financial assistance through monthly government support for family
Hospital Provided Support for families	<ul style="list-style-type: none"> • Providing social support via family visitation • Recreation/play therapy • Religious support available • Social Work support • Referral to home health care • Relief services for parents • Support from physician staff • Patient relations specialist • Patient educators/consultants
Home Health Support for families	<ul style="list-style-type: none"> • Provides extended treatment at home • Provides education support to caregiver
Role of the Paediatric Nurse in supporting families	<ul style="list-style-type: none"> • Education to support parental understanding and care for child • Assessment of parent stress/well-being, and monitoring • Communication of situation, procedures, and diagnosis • Ideal to support both parents (i.e. not ignore father because he is not present at all times)
Factors affecting family stress and coping	<ul style="list-style-type: none"> • Positive effect of (reduce stress & increase ability to cope): • Parent education • Negative effects of (increase stress): • Only mother allowed to stay • Language barriers to communication • Worry about siblings at home

6.3.1.1 Saudi health care system support for families.

The first thematic category identified from the analyses was developed from nurse participants' responses related to their perceptions of the support received by families from the Saudi health care system. From the data, the participants identified that an important area of support the family received was through the provision of free health care through the Saudi health care system. Government hospitals (not private) provide services free of charge to Saudis. This was expressed by nurse participants as being a significant support to the families:

This is a governmental hospital, so it's free of charge. All the Saudi families can be treated free. (Participant 2)

A further explanation of the extent of this support and what this includes is illustrated here:

They are really supported by the hospital, their medications, food, even the special formula they need. They are supported by the hospital, as it's a free of charge hospital. (Participant 7)

In addition to financial support in the form of free health care, participants reported their understanding that the government also provided a monthly salary for those who qualified and met eligibility criteria. This is to help support the family financially while taking care of a sick child:

We are a free hospital. But I heard from some parents that they are receiving a monthly salary from the government. (Participant 5)

The fact that this monthly salary is not available for all parents is illustrated in the following:

I think some families are getting support from the government, but not everyone. Only the ones whose applications to get support are accepted by the government receive this support. They will give them a monthly salary to help them live a normal life and take care of the sick child.

(Participant 2)

In addition, the nurse participants identified that the parents received other support in the form of free home health care once the child was discharged from hospital. It is clear from this quote that this does not necessarily apply to all families:

We have the home health care. If they are accepted by the home health care, they will be supported and then they are supported here if they are admitted in the hospital. (Participant 7)

As a government hospital, therefore the Saudi health care system support allows the hospital to provide patient and family support in a very comprehensive way. The extent of this support can be summarised by the following:

I think the hospital is providing the full support to the family. First of all, this hospital is a free hospital. Patients do not pay. Second thing, medications and all hospital supplies are free. Also the feeding, formulas, the milk, they are all free. Next thing, when the patient is discharged from the hospital all supplies are provided for them to take home such as medications and other medical supplies. If the patient requires, let us say

a suction machine, they are provided with it, if they need professional follow up they are also provided with the Home Health Care facilities. So I think the hospital is doing the best provision when it comes to [caring for] the patient. (Participant 9)

This leads to a discussion of the nurse participant responses related to how the hospital provides other forms of support for these families.

6.3.1.2 Hospital-provided support for families.

The second category identified by the nurses' responses related to the specific support given to families from the hospital. From the data, it was clear that the family was supported in different ways. Firstly, the nurse participants described, in terms of hospital support to the families and parents of chronically ill children, how important providing visitation opportunities for family and friends was. The following examples provide the perceptions and experiences of the nurse participants with regard to the notion of visitation. These examples highlight the importance of visitation hours and allowing siblings to visit:

Yes, family members, they come during visiting hours ... now there is a new system that twice a week on Mondays and Thursdays, siblings are allowed to come ... family can gather to talk and support each other. (Participant 10)

Such was the importance of permitting visiting opportunities that one nurse describes it in this way:

This can be viewed as you having family reunion and they can have a private area to meet. They can be with them for few hours in one room.

(Participant 1)

Providing a private areas for the family to meet facilitated these visits and enhanced the visits. The benefits that these visiting opportunities provided is the supportive effect they have on the parents, particularly the mother. This is described in the following:

From the visiting hours we can see that the mother can receive support from her family and friends, which makes her more comfortable and less stressed. (Participant 2)

The effect that these visits can have on the mother is clearly illustrated in the following:

But the most important thing is that they can connect during the visiting hours where the parents can feel a bit relieved and see that they are receiving support from their friends, relatives and other family members.

(Participant 5)

As described by the above comments, through the provision of visiting opportunities, the mothers who stay with the sick child all the time have the opportunity to reconnect with family and friends. This then provides them with support and also an avenue for stress relief. Therefore, visitation privileges represent a significant support mechanism for the parents, and especially the mother who is staying with the sick child.

Another support offered by the hospital is the availability of the playroom, plus having play and recreation therapy. The benefits of the play and recreation space and therapy were described as supportive to both the patient and the mother (or both parents in fewer situations). What was available is explained in the following:

We have the playroom area with a specialised therapist. The nurse therapist is the one in charge of this, the playroom. She will assist the patients to the playroom area where they have coloring books, and other limited toys. (Participant 8)

The nurse participants also reported that the hospital provided access to religious support if desired. This support was in the form of being able to request a visit from religious people or leaders, as was described:

Sometimes Saudi families, some of them, not everybody, they request a religious person to come and read the Holy Qur'an and make some prayers for them. (Participant 6)

The nature of the support provided by this religious person is described in the following:

Many families have been visited by religious people where you call it here 'Sheikh', who comes and makes some prayers and reads the Holy Qur'an. So this is what I know about the religious leaders' support. (Participant 5)

In addition, the hospital respects the religious practices of the patient and their family and supports availability to adhere to those practices, by providing what is needed to do so. The extent of this support is described in the following:

And here we allow parents to observe prayer time. We have a specific direction where you have to pray. In each room you can see where the arrow is, where you have to face to pray. We have lots of religious doctors here as well. So when it comes to religion, it is being practiced, observed and followed by parents and Muslim hospital staff. (Participant 9)

Lastly, support is also received from social workers, as well as other professionals at the hospital, such as hospital-patient relations specialists and hospital educators. Basically the role of the social workers is identified in the following:

Social workers are also helping. They are the ones providing the coordination of the discharge needs of the patient at home. (Participant 3)

In addition, the social worker provides this coordination by undertaking the following:

We can call the social worker who organises the home health care and hospital educator who can teach the mother to provide care for her child. The social worker will try to look for solutions for the needs of the family of the sick child. (Participant 4)

Not only do the social workers provide this coordination role, they provide support. This supportive role and its importance is illustrated here:

They will encourage the mothers to be strong and think positively about their child's health. Yes, the social workers provide all the needed support. Parents will rely on the social worker, the social worker will first assess the family and if their situation with their child's illness needs home support and care they will provide it, because not all of the families are able to be provided with help and support, so the social worker assesses the situation of each family. They will go to the parents /mother. They will interview them. So from the assessment, and if the family is from a very low socioeconomic class, they will provide the support.

(Participant 5)

One of the areas the social worker supports is access to home health care support. The support given through home health care is described in the following category.

6.3.1.3 Home health care support for families.

The third category was developed from the nurse participant responses and related to the home health care support provided to families. The data revealed that home health care provided much needed extended treatment in the home (after hospital discharge) and education to the parents and caregivers. However, for this service, the patient and family had to meet certain criteria, for which they were evaluated while in the hospital. The criteria used to assess the eligibility is illustrated in the following:

Home health care. Not all discharged patients are eligible for home health care support. Some only, if critical and the patient needs suctioning and other complex nursing procedures, they will be provided with home health care. (Participant 5)

In addition, home health care is not restricted to Saudis but is available to expatriates as well. In other words, it is available for anyone in need of care beyond their hospital stay:

The home health care is not only for the Saudis, that is for everybody non-Saudis and Saudis. Both are treated equally. (Participant 6)

For the expatriate population, this home health care is extended to include provision of suitable housing. The reason that this housing is provided is illustrated in the following:

Sometimes patients who do not have a good housing arrangement such as expatriate labourers, they may be provided with a house suitable for the patient to be transferred to and home health care will be delivered to the patient. (Participant 6)

In addition to health care support in treatments, medications, and equipment needed, the home health care services provide education to the caregivers to strengthen their abilities and confidence in providing care to their child at home:

The home health care, I think they have Arabic speaking people that can help the mother to cope with her chronically ill child. Mothers are taught in the hospital on how to care for their children so that they can provide

the required care for their children when they are discharged from the hospital. (Participant 7)

6.3.1.4 The role of the paediatric nurse.

The findings of the fourth category are central to the study. This category was developed from responses related to the perceived role of the paediatric nurse in supporting the patient's family. In addition to providing the day-to-day care of the patient, the paediatric nurses described another important role they had in supporting the parents and family of their patients. This was in providing education to the parents, to support their understanding of the illness and being able to care for their child. The importance of this role in supporting the parents is described in the following:

The first thing is the education, education about the case. What [can] they expect from this child? Okay. What should they expect and as far as the care for the child, we should teach them. The education is important.
(Participant 10)

Further highlighted in the data was the need to provide open communication and education to the parents, particularly the mother, who stays with the child. This included providing the opportunity for the mothers to ask questions and respond accordingly:

As a paediatric nurse here in Saudi, I am very frank and open with the mother. What I am able to explain, provide to them regarding the case of their baby or child I will, at least, I am here to explain what I know or understand about the case. I am here to provide care as a paediatric

nurse and to listen if they have something to ask because they have the right to ask and to know the case of their children. (Participant 5)

This education included communication with the parents regarding the current situation, and explanations of the diagnosis received, where possible. The importance of this education is based on the need for parents to provide care for the child once they leave the hospital. One of the nurses described that the parents (specifically the mother) need to take on the role of the nurse in providing care to the child and the extent to which this might be the case, by providing examples of what might need to be done:

The explanations on the situation of the child, especially the initial diagnosis, any way we can give very simple explanation about the illness of the child. These families should really understand the real situation of the child, because it is chronic, sometimes terminal. The nurse should also explain, like the doctor, they should explain especially the nurse should be more on teaching. How to do the dressing? How to give bed bathing? These are nursing issues. Oh also especially oxygen therapy, how many litres does the baby need? Also, providing oxygen and pulse oximeter. So the role of the nurse, especially, is teaching the mother to be independent. Yes. She should know about it. Parents both should be father and mother, at the bedside of the baby, but hospital regulations do not allow it. (Participant 1)

This was similarly explained by another participant, who described how the nurses use their time with the mother to help her understand what she needs to do to take care of her child:

The mothers are always staying in the paediatric ward. So we are getting time to talk with mothers. Most of the chronically ill children are frequently coming in and out of hospital. So we are getting time to get to know the mothers and talk to the mothers and we are getting information from the mothers about their family history and all. We are talking to the mothers and we are giving them support. So we are explaining to the mother to take care of the baby or child at home, to give the medications at the exact time. (Participant 3)

As the mother is allowed to stay with the child, the nurse is also able to assess and monitor the stress levels and health of the mother during her stay. The nurses can then refer the mother for treatment if necessary and of course encourage them to go home and sleep. This was explained by the following:

So if for example, the mother is not feeling well, she is crying all the time, feeling stressed we will ask her if she needs help. We also advise mothers to go home and take a rest to relieve them from the long hospital stays because this is our role to take care of people and their children. If you are a paediatric nurse, you have the experience, knowledge and skills to assess how the mother is feeling. So we are used to taking care of the

children and their mothers. I usually encourage the mother to talk, and we usually spend time with the mothers. (Participant 2)

Finally, the nurses commented on the importance of ideally providing support to both the mother and the father, despite the father's relative absence due to not being allowed to stay:

Both parents the father and mother, should be at the bedside of the baby. But here in our hospital, we only allow the mother to stay and sleep in the hospital. Generally speaking, it should be both parents, and we should support both parents and the patient. (Participant 1)

The reasons why it is important to include the father and the need to support the fathers as well as the mothers is illustrated here:

The mother is only with her child because males are not allowed in at all times. But during the visiting hours, the fathers are allowed in. Not only the mother is taking the care of the baby, the father is also taking care of the baby. We cannot neglect the fathers; they are also worrying about their child's health and taking care of their children and babies. (Participant 3)

6.3.1.5 Factors affecting family stress and coping.

The fifth and final category developed from the participants' responses related to the nurses perceived factors that affected family stress and ability to cope. From the data, the nurses expressed that the most significant strategy used in supporting the parents to have less stress, enabling them to cope with the stress that they had, was

providing parent education. This was also noted in the role of the nurse in the section above; however, in this instance it is referring to the effect this had on relieving the mother's stress. The importance of this education in assisting the parents stress and coping ability is illustrated in the following:

First of all, the nurse should also read about the condition of the patient, the diagnosis of the patient so she can educate the mothers, and she will try to help them cope with the ill patient and try to relieve their stress by educating them. Let them understand the condition of the patient, the treatment, and how to deal with that disease. It is really very important to understand the diagnosis and prognosis of the patient, accept the child's illness and have the courage to take care of the sick child so that they can cope. (Participant 4)

There were also factors identified from the data that increased the mothers' stress. As noted in the previous section, the mothers are generally allowed to stay, but the fathers can only visit during specific hours. This hospital limitation exerts stress on both the mother, who has no relief, and the father, who is removed from the situation and is not able to help care for the ill child. One of the nurses noted the willingness of some fathers to help support the mother. Here, the inability to stay due to hospital policy caused some frustration:

Of course, most of the time the fathers want to stay and help. Sometimes the father will try to stay and send the mama home because she is tired and not feeling well. 'Can I stay in the hospital instead of her?' the father

asks. Some fathers are willing to stay here, but what can we do? Policy is policy. It is really the mother who can stay not the father. (Participant 8)

Not only is the mother on her own at the hospital, often without the support of the father, but she also often has other children at home to worry about. Here again the nurse can help. The role of the nurses to help decrease this added stress is illustrated in the following:

Of course, she has other children at home to look after as well. She cannot focus only on her sick child because she has other children waiting for her at home. Now, since the patient/child is in the hospital, we, nurses are here take care of her baby in her absence. We try to convince the mother to go home for a while and attend to her other children. (Participant 9)

Lastly, the nurses also noted language barriers to their communication with families, making education and emotional support by the nurses more difficult. Families are Arabic speaking and do not necessarily speak English well. Paediatric nurses are predominantly expatriate and English speaking with little understanding of Arabic. The different Arabic dialect is another factor that contributes to this language barriers:

Yes, it is not easy for us; number one problem is the language barrier. We cannot understand each other, as we cannot speak Arabic well. And sometimes, the parents do not understand the English language. (Participant 7)

The solution to the problem was outlined by one of the participants:

The patient relation specialist is called in to assist with translating because of the language barrier. Maybe some parents think I am not that approachable, because of this language barrier. Ouffff it is very difficult for them and for us. Because sometimes many patients who are Bedouins from rural Saudi areas cannot really be understood although they are speaking Arabic but it sounds like a different language to us.

(Participant 8)

As noted by these participants, this language barrier affects their ability to support the patient's family through providing information, communication and education, which were identified by these study participants as an important element to reducing stress and improving the ability to cope among the parents and family.

6.3.1.6 Summary of nurses' interview findings.

The nurses' interview provided information on the provision of family support when dealing with chronically ill children which is provided on many social and structural levels, including the Saudi health care system through the hospital, home health care services, and the nursing and professional staff. Many factors were perceived to affect the level of stress in the family and the ability to cope with the stress of an ill child. These included the positive effect of education on the illness and caring for the child, as well as the negative effects of the imposed hospital restrictions where only the mother is allowed to stay with the child (not the father), language barriers with hospital staff reducing communication and education, and parental concern for siblings at home

while at the hospital caring for the ill child. From the variety of participant responses, several conclusions were drawn for the group as a whole.

Conclusions, in the form of overarching themes revealed from the analyses of the nurse interview data, were developed from the categories of the previous sections (Moustakas, 1994). These overarching categories describe how the participants perceived their experiences as a group (Moustakas, 1994), allowing for greater understanding of parental and family support received from different social sources throughout the experience of having a chronically ill child. The concluding themes and corresponding experiences provide the overall conclusions of the data analysis of the nurse interview data and therefore, these overarching categories were used to address the related research questions of the study (RQs 3–5).

6.4 Mothers' Demographic and Personal Characteristics

Twelve Saudi mothers of chronically ill children accepted being interviewed. Table 6.3 provides details of the age and education of each mother. The majority of the mothers were housewives and ranged between 24 to 37 years old. In Table 6.3, further details of the child's diagnosis, their age and duration of illness are provided. The most common diagnosis was found to be leukaemia and brain tumour. Children were aged from 12 months up to eight years. The duration of the illness was found to be from birth up to two years.

Table 6.3

Demographic Characteristics of Saudi Mothers

	Mother's Age	Education	Diagnosis of the child	Age of Child	Duration of Illness
Omm Farah	34 years	Housewife	Leukaemia	2 years	17 months
Omm Fatima	24 years	Housewife	Epilepsy	4 years	18 months
Omm Khalid	35 years	Housewife	Diabetic	8 years	1-2 years
Omm Sami	37 years	Educated, Employed	Brain Tumour	4 years	5 months
Omm Adel	32 years	Housewife	Hydrocephalus	16 months	From birth (7 months)
Omm Ahmad	27 years	Housewife	Leukaemia	3 years	17 months
Omm Hassan	25 years	Housewife	Leukaemia	2 years	16 months
Omm Mohammad	32 years	Educated, Employed	Epilepsy	7 years	1 year
Omm Mona	28 years	Educated, Employed	Leukaemia	5 years	14 months
Omm Afaf	27 years	Housewife	Cystic Fibrosis	2 years	12 months
Omm Tala	31 years	Educated, Employed	Brain Tumour	12 months	9 months
Omm Sara	28 years	Housewife	Brain Tumour	2 years	4 months

6.4.1 Mothers' interview findings.

In addition to the nurse interviews as a means of addressing research questions three to five, the study incorporated qualitative analyses of interviews with 12 mothers of chronically ill children. As with the nurses' interviews, data from these interviews

were used to develop several categories related to the experiences of these mothers, their difficulties, ways of coping with the illness, and the support they received from different sources. The results of the mother's interviews supported five categories, which included: experience with the diagnosis, parent difficulties, parent/family acceptance and coping, and desired support. Table 6.4 illustrates these categories with an overview of what constitutes them.

Table 6.4

Parent Interview Thematic Categories and Themes Revealed

Thematic Category	Themes Included
Experiences with Diagnosis	<ul style="list-style-type: none"> • Disbelief or denial • Shock • Fear • Not given much information or did not understand • Upset/anger
Parent Difficulties	<ul style="list-style-type: none"> • Financial difficulties • Psychological need for support • Caring for and giving attention to siblings • Loss of social relationships • Emotional volatility
Parent/family Acceptance and Coping	<ul style="list-style-type: none"> • Rely on God, faith, prayer • Help and Support of family • Reading the Qur'an in prayer • Talking to other mothers of sick or disabled children • Siblings and family have accepted, adapted, and help me • Support of friends • Support of husband • Support from health care professionals
Desired Support	<ul style="list-style-type: none"> • More information from doctors • Moral and emotional support from hospital/staff • More support from husband

6.4.1.1 Experiences with diagnosis.

The first category revealed from the analyses of the mother interviews was developed from mothers' responses related to the initial experiences of the diagnosis and learning of their child's illness or disability. Participants commonly reported feelings of disbelief or denial, shock, fear, and feeling upset when they were informed of their

child's diagnosis. These feelings were made worse because of a lack of information from the doctors/staff or a lack of understanding on their part of the information given.

Parents most commonly reported initial feelings of denial or disbelief of the situation as they were informed of the diagnosis of their child. This feeling of denial or disbelief was exhibited in a number of ways, as illustrated:

At the beginning, I was trying to convince myself that my child's illness is a temporary issue and that I did not even need to take her for check-ups. I thought that it is nothing and it will go with time...ehhhhhh... (Omm Farah)

When Mohammad did his first check-up, they told us we need to do more investigation, as he might be epileptic, but I continued believing that there is nothing and no need to do anything. (Omm Mohammad)

A common denial response that the mothers described during the interviews was to run away as a strategy from something they could not handle:

When they tell me something that I cannot face, I run away from it. This happened to me when they first told me that Mona have cancer. I blocked it and I did not want to believe it. (Omm Mona)

Some women expressed that they ran away and wanted to deny the diagnosis by thinking of other things to block this out. Religion also played a strong part in their response:

Sometimes I face problems and sometimes I run away from them. But when it came to hearing that my child is diabetic and will be so all his

life, I was afraid and I couldn't believe it and I tried to think of other things to forget this issue, poor Khalid he is so young. I try to think this is the will of God and God will take care of my son. (Omm Khalid)

Such was the disbelief about the diagnosis with one mother said that she just laughed at the doctor:

When the doctor told me that Tala has a brain tumour, I looked at her for a second and then I said: 'You are kidding!' and I started laughing. I did not want to believe that what she is telling me is true. (Omm Tala)

As part of this disbelief and denial, the mothers expressed that they were shocked from being told their child had such a serious diagnosis:

But later, I couldn't focus, couldn't walk because I was very shocked and I didn't believe that my daughter is so sick as she looked good and amazing and there was nothing wrong about her. So, I kept looking at her and thinking that the doctor might be wrong. (Omm Farah)

So shocked were some, that this impeded them hearing what the doctor was telling them.

This was a shock for me as I wasn't really expecting or believing that something was seriously wrong with him. I did not understand any of what the doctor said. It was and still is a shocking moment and I couldn't believe it. Everything the doctor was saying wasn't clear for me. (Omm Ahmad)

This feeling quickly then turned to being frightened, scared and worried:

When I knew that my child is very sick, ...sniff... sniff, I felt scared and upset. I was scared of what was going to happen to her. I was worried about how can we deal with that. I was scared of what others would think and what their reaction would be to my child especially my family. I felt anger, fear, and denial and was very very upset. (Omm Farah)

Part of that worry of course related to their other children:

I felt scared and I was upset. I was concerned that maybe other children in the family would also have the same disease. I was scared of what was going to happen to him. I always heard that most people who had cancer died. I was also scared of what others would think and what their reaction would be to my child—especially my family, my other children. (Omm Sami)

All of this contributed to the mothers not being able to understand what the doctors were saying to them:

Since the beginning, I felt that Fatima is not feeling well but I did not want to take her to see a doctor because I kept on convincing myself that there is nothing wrong with her and she will get well soon I do not know if she will. I do not understand what is happening and I do not know what the doctors say to me. (Omm Fatima)

This was contributed to by the fact that sometimes it took some time to get a diagnosis. On top of that, participants described not being given much information at the time of diagnosis, which seemed to increase these other negative emotions:

We had lots of visits from the paediatricians. Unfortunately, none of them knew what exactly was wrong with my baby, what illness does he have? They only said at the beginning that 'he is never going to walk'. The tests that they made were many and they did not explain to me, which made me very frustrated. We were desperate to find clues to what was going on with him, but really nothing was emerging. (Omm Adel)

The mother not being on her own during this time helped immensely as illustrated:

I remember that I was crying a lot and not really listening much when we first took him to hospital. I was and still in a stage of shock. I had a horrible numb feeling and thanks God my husband was with me, so he was the one asking the questions and he was asking about more information about our child's condition. We were not told anything although my husband was asking the questions. (Omm Hassan)

This lack of information was perceived by the participants as contributing to greater stress and difficulties.

6.4.1.2 Parent difficulties.

The second category was developed from responses related to the specific difficulties encountered by parents through the experience of dealing with their child's chronic illness or disability. In nearly all the mothers' interviews, participants' noted financial difficulties associated with their child's illness. The data illustrated the various affects that this had on them:

Financially, it's very difficult especially if you have an ill family member.

It's hard to meet all the needs. (Omm Farah & Omm Sami)

The impact of these financial difficulties also affected the other family members, as illustrated:

We have financial problems and this makes other children sad, as they do not get what they want. (Omm Khalid)

For some, the financial difficulties stemmed from losing their jobs. For example, the following parent participants described their experiences and the impact this had on them. The various reasons that these women lost their job is illustrated in the different comments:

I had to miss some work, and when my boss found out that my child had brain tumour, she made me quit, as they don't want me any more around. (Omm Sami)

Once my work knew about my child medical condition, they asked me to quit. That was a very big shock for me as big as that of my child illness. (Omm Mohammad)

I lost my job because when they knew that my child has leukaemia and I need to travel with her abroad for treatment, they found a silly reason to terminate my contract. (Omm Mona)

When Sami started the treatment, I felt very weak as I am the one who is taking care of, so I thought of leaving my job, so I took sick leave, but the

big shock was when they told me we do not want you. I was a good teacher (started crying). I could not handle it because I love my job so much. (Omm Sami)

In addition, some mothers felt that they had lost their social relationships due to their child's illness or disease. For example, Omm Afaf and Omm Fatima mentioned that people stopped visiting them, while Omm Mohammad and Omm Tala mentioned that they did not want to see anyone. The various reasons for this are illustrated in the following:

My relationship with my neighbours used to be very good, but now things changed I do not see them frequently because they are busy and they do not have time to visit me, people would like to go have fun and laugh not where they feel sad. (Omm Afaf)

Our social relationship changed, I am not doing any social visits because of Mohammad's illness, even I do not want people to come for a visit, so I try to find lots of excuses to delay their visits. (Omm Mohammad)

I stopped communicating with my friends, and I know that some friends try to avoid being in the same place with a sick person. So I stopped talking to anyone because I hate sympathy. (Omm Fatima)

The effect of this social isolated is reflected in the following:

I used to work every day, after I left my work, no one from my colleagues is supporting or even asking about my sick child or me. I feel so lonely. (Omm Tala)

One of the difficulties that mothers expressed during the interview was this emotional instability. For some mothers, this in itself was distressing:

Once I knew about our daughter's sickness, I have changed a lot; I got angry and started to shout a lot whenever anyone says one thing to me. I start crying. This is very hard. Omm Farah started weeping. (Omm Farah)

Omm Farah also discussed the psychological need to express her feelings, but lacking the everyday availability of family to be able to do this:

Psychologically, it will be great to have someone to talk to and express your feelings but unfortunately no one has the time here to listen to you all the time. Of course there is my family, but they are not free to come every day and listen to me and support me. (Omm Farah)

In addition, this participant offered the perception that she needed to be the emotionally strong member of the family to support the patient and keep them motivated. At the same time, they struggled to spend quality time with their other children and then dealt with the consequences of not being able to do that:

Emotionally, there should be a stronger person in the family to keep the family motivated and feel stronger and this is very hard while you are dealing with a chronically ill child. (Omm Farah)

Mothers also reported depressed feelings. Omm Khalid felt depressed because she was not able to fulfill her role as a mother, wife or as a family member:

I have great children and my relationship with them did not change, but I feel very bad because I used to cook and take care of everything in the household, but since Khalid got sick, I cannot do that much for them. I am taking care of him more than the others and that lead to problem dealing with them. (Omm Khalid)

Omm Farah felt emotionally depressed because she lacked critical support from her husband and her family:

I felt depressed and stressed most of the time because I can't find my husband when I need him. He is always busy working, so most of the time I am the one who is taking my sick child to the hospital and staying with her alone. (Omm Farah)

The general lack of support felt by these mothers was noted, contributing to a sense of isolation:

It was really hard on me, as I have not been receiving any support from anyone around me especially my family. There was no support from the hospital as well. Although we are receiving free caring services, it's not the only type of support that we are looking for. (Omm Sara)

The changes to the family dynamic may be significant, as a result of having a sick child. Some participants noted the problem in trying to give their other children enough attention and care while spending most of the time with the ill child:

It's really hard to take care of all children while you are giving all the attention to your sick child. (Omm Hassan)

The reasons for this are clearly illustrated in the following:

I have problems dealing with my other children. They feel that they are not important as Adel and I am not taking care of them as I do with Adel. I tried so many times to explain to them that their brother is sick and we should take care of him more. They are always asking me why we are not spending time together as a family and why my brother is not playing with us? It's really hard and frustrating to deal with all this. (Omm Adel)

Lastly, mother expressed that they were having difficulty and concerns for the other siblings in the family. The extent of this concern is clearly illustrated in this comment:

Also, it is difficult because my family have to be very careful and avoid getting closer to Sami. It actually worries me sometimes that maybe my child will never get better. (Omm Sami)

In addition, one participant described feeling alone and isolated, having to care for the sick child, the other siblings, the husband, and the household by herself with no help. She noted she would like more help from her husband and from her family to feel less stressed and more relaxed:

It's really stressful to have a sick child, other siblings to take care of with their needs, taking care of the house (cleaning and cooking) and taking care of your husband. You have to do everything by yourself, as there is no one here to help you. (Omm Farah)

It was clear from the data that participant's children were cared for by the nurse, but there was a lack of care or concern for the parent staying with the child:

I have not had that much support. I had to stay so many days alone at the hospital with my sick child and no one was looking after me. (Omm Hassan)

The only needed help from the hospital is moral and emotional support. I think mothers need to feel that they are getting help, someone is asking about her, how does she feel, if she needs to talk to anyone like that. The only focus here in the hospital is the sick child and no one is caring about her parents and especially the mother. (Omm Adel)

All the factors that contributed to the parents' difficulties of changing family dynamics, stressors, and the need to continue to set family limits and participate in activities are illustrated in the following:

It's extremely difficult for parents to have a child with chronic illness. Having one ill family member impacts the whole family system and changes the dynamics of the whole family. How you spend time, how you spend time with each other, how it can impact your financial resources, how it can create a tremendous amount of stress. Also it's very difficult to set limits with your child when your child is sick. All these things cause stress for all family members; limits, activities, things that we all like to do that we can't do together because we have a child with a chronic condition that affects everyone in the family. I suggest families to

normalise their lives as much as possible. Children with chronic illness are children first who live with their illness and it's really important that the rules of your family, the activities of you family and all the things that make family and life rewarding for the children who don't have chronic illnesses need to be the way that you live with your family when you have a child with chronic condition. It is easier said and be reminded of this all the time than being actually done. (Omm Sami)

6.4.1.3 Parent/family acceptance and coping mechanisms.

The third thematic category revealed from the parent interviews was that of parent and family acceptance of the problem, and the coping mechanisms employed to help them get through their child's illness or face the child's disability. For the majority of participants, reliance on God, faith in a divine plan, and prayer served as their most significant coping mechanism. The mothers in this study reported coping with the stress of having a chronically ill child through the help of their faith, prayer (reading the Holy Qur'an), and relying on religious leaders for support:

I believe that God has given me the strength to deal with this problem. I pray to God every second and ask him to give me the power and strength. Praying and reading the Holy Qur'an make me relaxed and calm. I actually depend on God in everything, and this is the most important thing in life, I pray a lot and ask God to make my daughter well soon. I totally rely on God, as I believe that God has the cure for everything.

When I listen to the Sheikh reading the Qur'an and make some prayers, I feel relaxed and calm. (Omm Farah)

These mothers used religion as a means of coping, and they perceived it as an effective coping mechanism. So important was religion that most of the mothers believed that their life and recovery were in God's hands. The extent of this belief is clearly illustrated in the following:

I do not trust what the doctors tell me about my daughter's illness, I am depending on God's healing abilities. (Omm Farah)

I always prayed to God and ask Him to give me the strength and help me. (Omm Farah & Omm Adel)

Religion plays a very important part in our lives, I always pray that God will lighten our way, and believe me, whenever it gets complicated, we find a way to solve our problems. (Omm Sara)

When I feel weak and I start crying, I start praying to God and ask him for His mercy, and I believe that nobody will die until his/her time comes, take it as a rule, no disease, no problem, nothing only when your time comes you will die. (Omm Sami)

This strong religious belief was an immense comfort to these mothers, as they believed that this was destiny. In other words, what will be will be:

My husband keeps on telling me not be sad, this is from God, and I believe it is so. I have peace inside me and I am putting everything in God's hands. What makes me stronger is that I believe that it is

Mohammad's destiny and if God has written for him not to get cured we will accept it. We pray that God will cure him and he will be ok soon.

(Omm Mohammad)

Thanks be to God, I believe that everyone has his/her destiny and we have to accept what God has written to us. I also believe that God helped me, accepted my prayers and had supported me, thank God for everything. I am reading the Holy Qur'an every day and pray all the five daily prayers, and I always ask God to help me and cure my son and I am sure He will. I always pray to God to cure my son from his disease and to strengthen my belief in Him. I know that no one will die if it is not his/her day, but I keep on asking God to cure him soon. (Omm Hassan)

Most of the mothers believed that by praying and reading the Holy Qur'an, they would become relaxed, calm and be able to overcome their uncontrolled emotions:

Praying and reading the Holy Qur'an makes me relaxed and calm. I actually depend on God in everything, and this is the most important thing in life, I pray a lot and ask God to get my daughter well soon. When I start reading, I forget my child's issue and I feel relieved. The Qur'an is very close to me. I read the Qur'an every day as it has the cure for everything and had created the medicine for every disease. (Omm Farah & Omm Afaf)

I started praying a lot and this helped me, God gave me the strength to continue. When I feel upset, or angry, I start praying and I find peace.

(Omm Ahmad)

I take my time in praying and I visit Makkah and Madina several times and ask God for His help and support. I always bring from Makkah Zamzam water (Holy Water). I use it when I give a shower to Khalid, I believe in this and I am convinced that the Holy Water is protecting him.

(Omm Khalid)

In addition to God, participants described how important the support of their mothers was:

I tried to cope by the help of God and my mother. My mother offered me so much help and support; and she is the one who makes me stronger and able to deal with this huge problem after God. I know that everything is from God. (Omm Farah)

Another significant coping mechanism that the participants described was the support of family. The reasons why family was so important are illustrated in the following:

[I cope] with the help and support of my family. Well, they do so much. They make sure I do take care of myself, do some of the housework, and take care of my other children. (Omm Sami)

Getting support from your family and friends are the most important thing because it gives you strengths and power. (Omm Ahmad)

Other family members that the participants described as important support was their sisters, brothers, husband and mother-in-law:

My sister is very helpful and she took a very big load from my shoulders when I am in the hospital, even she stays overnight to keep me company and tell me jokes. (Omm Afaf)

My brother and sister were very helpful. They kept on calling me, visiting me and taking care of my other children and promised to not leave me alone until Adel gets well. (Omm Adel)

My husband supports me a lot and my mother-in-law is of great support. They took care of my children when I used to go the hospital to take care of my son. (Omm Khalid)

Even though difficulties were expressed in the data regarding the mothers' ability to care for their other children, their other children were also supportive:

My older daughter was always trying to make me strong, support me emotionally and always taking care of me and her other siblings. (Omm Mohammad)

One of the participants who had two other children, described how they supported her:

Farah has two older siblings. It was really hard on them to believe at the beginning but you know, thanks God they adapted with it. They were trying to help me as much as they can. (Omm Farah)

Finally, mothers in this study described the support received when talking with and visiting other mothers with sick or disabled children. The reasons why this was so helpful are illustrated in the following:

I feel really relieved when I talk to some mothers of sick children and share the same feeling. We always can listen and support each other. Actually when you meet a mother who has a sick child with the same illness as yours, there will be a connection and understanding between the two of you. When you talk to other parents with a sick child, you share so much. They might go through the stages that you are going through with your sick child, or is currently at the same stage that you're at. Being able to talk to other parents just reassures you that you are doing the right thing. If we could teach each other how to manage it is something helpful. (Omm Hassan)

In addition to all of this support, parents described receiving support in the form of explanations and checking on them from the health care professionals. The reasons why this was helpful are described here:

The hospital medical teams were good. They explained to me everything and I felt better as they gave me hope that things will be better. The nurses are good as they used to come every now and then when they see me sad and feeling lonely and they start talking to me. (Omm Farah)

6.4.1.4 Desired support.

The fifth and final thematic category reflects the perceptions of needed support and desires of parents for additional support they are not currently receiving. Common responses highlight the need for doctors and medical staff to provide more information in terms of what is happening with the child, as well as information supporting the development of parents' ability to provide care for their child and what to expect in the future. Mothers also described the need for more support from their husbands.

The data identified that participants noted the need for doctors to be more helpful in providing explanations and information about the children, procedures, and other pertinent information:

I wish the doctors would deal with us differently, if you do not ask they will not inform you of anything and I always try to prepare questions to ask them otherwise they will not tell you anything. (Omm Hassan)

From the data, the mothers also expressed areas where the health professionals were not helpful, as illustrated:

Let me tell you in what sense they did not help. They did the surgery for Mona but after that, they did not discuss my feelings, emotions, or what to do or expect. (Omm Mona)

Some participants discussed that although the hospital provided care free of charge, and the necessary support and care for the sick child and they were very grateful for this, there was a lack of concern and care for the parents:

The hospital is providing the needed help for example, it's free of charge, and the medication and treatments are free. The only needed help from the hospital is moral and emotional support. I think mothers need to feel that they are getting help, someone is asking about her, 'How does she feel?', if she needs to talk to anyone like that. The only focus here in the hospital is the sick child and no one is caring about the parents and especially the mother. (Omm Sara)

The data clearly illustrated that the mothers want to be asked if they were all right:

Mothers of sick children need help and support. They want to be asked how do they feel and if they need to talk to anyone. (Omm Adel)

These mothers described feeling left out and needing moral and emotional attention and care:

I wish that there were someone who can take care of me and listen to my needs. I become more upset because when the doctors come to see Sara, they never ask about how I feel, do I need any help or support or do I need anything? I feel that we are not important as the patients so that is why we are left behind. (Omm Sara)

Another support that the mothers described as needed was more support from their husbands. For example, Omm Farah noted:

Actually, I would appreciate if I got more support from my husband as well. Off course we both feel pressure and stress but he is rarely helping

or supporting me maybe because of the nature of his work, I don't know.

(Omm Farah)

The mothers felt that it was also important to receive information on providing care for their ill children, as they will be expected to do so at home. There was also reportedly little information offered about social work or home health care:

We never heard about social workers or home health care. No paediatrician or even the hospital told us about it. We heard from other parents that the social workers and the home health care are providing help for family with sick children at home. (Omm Adel)

The importance of this need is clearly illustrated in the following:

The biggest challenge we have had raising Ahmad by working with professionals. It was really hard for me and Ahmad's father to know how to deal with his condition and what does he really need help with. (Omm Ahmad)

This support for not only for themselves but for their family, as described:

About the government, we hope that the government can help us and provide more support. More than the need of the free care services; we need emotional and social support. Actually no one is caring about the other family members. We are trying to support and strengthen each other but it's really hard, we need support from others as well. As I told you, if the hospital and the government is supporting and taking care of the other family members, we will feel much better. (Omm Farah)

6.4.1.5 Summary of mothers' interview findings.

As with the nurses' interviews, data from the mothers' interviews were used to develop several categories related to the experiences of these mothers, their difficulties, ways of coping with the illness, and the support they received from different sources. The results of the mothers' interviews supported five categories, which included: experience with the diagnosis, parent difficulties, parent/family acceptance and coping, and desired support. Similar to the nurse interview results, the concluding categories and corresponding experiences provided the overall conclusions of the data analyses of the mother's interview data. These themes will be used in conjunction with those of the nurse interview data to address the related research questions of the study (RQs 3–5).

6.5 Summary

This chapter has presented an analysis of the themes raised by the nurses' and mothers' interviews. Bringing together the conclusions from the nurse interviews and the mothers' interviews yielded several final overarching themes that serve as conclusions for the qualitative analyses. These themes are as follows.

The Saudi health system was perceived to support families by providing financial assistance in the form of free health care, support for home care services, and monthly financial support to families to allow the parents to care for their ill child; however, there was a continued need for moral and emotional support for parents and other family members from the health care professionals.

The hospital supports families and patients in addition to patient care by providing social support through visitation with family and friends, recreation/play

therapy, availability of religious support, social work support, and referral to home care services, parent relief services, and support of professional staff. With parental needs highlighting social supports as critical, continued hospital support for social programmes such as visitations (as well as perhaps parent support groups to facilitate discussions and social contact between mothers of ill children). Additional support for changing family dynamics could be added to more completely address the difficulties experienced by parents and family members of child patients, such as allowing greater father participation in care.

Home health care supports families of ill children by providing extended treatment at home and education to support the parents and caregivers as they provide care to their ill child. Again, additional support for the changing family dynamics could be added to more completely address the difficulties experienced by parents and family members of child patients. A greater level of communication concerning children's current medical status, what to expect, and how to care for the children would further support the parents' autonomy in caring for their own child.

The paediatric nurse has a perceived primary role in supporting both patient and family health and well being through: direct care, education and communication to support parental understanding and ability to care for a child; evaluation and monitoring of parental stress during hospital stays and referral to treatment if necessary; communication of situation, procedures and diagnosis to parents; and ideally providing support to both parents despite only mothers staying with the child. Although supporting the parents is certainly a critical role in nursing, these results were not evident among

the parent interviews. More work on providing these types of parent care and reducing the nurse workload to allow more time with parents may be necessary.

Factors perceived to affect family stress and an ability to cope include parent reliance on God and prayer, and parent education and staff communication as positive influences, as well as the negative stressors associated with the hospital limitations of only allowing the mother to stay; language barriers between nurses and patient families; parent challenges related to limited social relationships; the changing family dynamics; and mothers' feelings of isolation and also concern for siblings at home while caring for the ill child in the hospital. In next chapter, both findings of the quantitative and qualitative data of the study will be integrated and discussed in detail, in light of the study aims and questions.

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Chapter 7 : Discussion

7.1 Introduction

This chapter will elucidate and contextualise the results obtained from the previous section of the study. It will also inform the aims and objectives of the research, which is to identify factors that lead to resilience among Saudi parents when faced with the adversities of chronically ill children in three main public hospitals in the Saudi Arabian region of Jeddah. This discussion will address the research questions in relation to findings from the study and current literature. The research questions are the following:

1. What are the factors that are associated with resilience among Saudi families with chronically ill children?
2. What are the relationships between family resilience and the chronic illness of a sick child?
3. What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities associated with chronically ill children?
4. How does the Saudi health care system assist in strengthening Saudi families when adjusting to the adversity associated with chronic health conditions?
5. What factors contribute to resilience in Saudi families?

In addition to discussing the findings of the study, this chapter will also compare the quantitative and qualitative results with those observed in the review of related resilience literature in Chapter 3. A review of previous studies that illustrated the

relationships among the variables measured will be performed. The purpose of this is to elucidate how the findings from this current study address the gaps of the existing body of literature. As previously mentioned in the literature review, there was a scarcity of comprehensive studies covering family resilience in the context of Saudi Arabia (as well as countries in the Middle Eastern region), which this research will seek to resolve.

7.2 Factors Associated with Resilience Among Saudi Families

This section will discuss the first research question, ‘What are the factors associated with resilience among Saudi families with chronically ill children?’ These factors were obtained from both the quantitative data and the qualitative data, through the interviews with mothers of children suffering from chronic illness.

7.2.1 Demographic factors.

One of the main factors associated with the level of resilience among the respondents was the demographic factor. Among the significant factors observed in these were the age of the mothers ($p < .001$), as well as their financial capabilities or income levels ($p < .001$).

The quantitative findings indicated a significant effect of the age variable, revealing that resilient parents tended to be older. Older parents were more resilient, due to their significantly higher levels of general self-efficacy (based on the GSE) and higher levels of social support (based on the SSQ). These observations are in line with the qualitative results, which found that mothers with lower levels of social support (based on the SSQ) and those who were relatively younger, experienced high stress and low QOL.

However, the age factor was not observed by any of the empirical studies in the literature review as being significantly associated with high stress or low QOL (Mutimer & Reece, 2006; Mutimer, Reece & Matthews, 2007; Thomas & Reece, 2006; Wade, 2007; Wade & Reece, 2006). While all these studies obtained demographic data from their respective respondents, none were able to make a connection between the ages of the participants and their levels of resilience. A possible explanation for this was that age (or any other demographic characteristics) was not a determinant of resilience in a vast majority of these studies. Another likely cause for this is the fact that many of the studies employed sample respondents who were relatively close in age, and as such, comparisons in the levels of resilience between parents or family members of different age groups could not be performed.

Another significant demographic factor affecting family resilience was the financial capability to pay for the costs associated with their child's illness. This financial capability is evidently linked to the family's income. The responses with regards to family annual income were more evenly distributed among the categories. Thirty-five per cent ($N = 43$) of the participants were earning an annual income of 55,000 SR and above, 16 per cent ($N = 19$) were receiving an annual income of 46,000 to 55,000 SR, 28 per cent ($N = 34$) were receiving 36,000 to 45,000 SR and 21 per cent ($N = 26$) were receiving 24,000 - 35,000 SR. In the qualitative interviews, mothers who were surveyed cited financial difficulties as a major difficulty they experienced. This was because having a sick child created a financial drain on the family which then made

it hard to meet all of the needs of the family, especially the other siblings who would not be able to get what they wanted all of the time.

This observation echoes similar findings from other research studies (Brown et al., 2008; Emerson, Graham & Hatton, 2006; Evans & Kim, 2013), who suggested that families with a child suffering from chronic illness are often characterised by low levels of resilience when the annual family incomes were low, as well as in cases of parental separation. However, these studies show high levels of marital conflict (Berant, Mikulincer & Florian, 2003; Berge, Patterson & Rueter, 2006; Evans & Kim, 2013).

The factors of family income and financial capability therefore were found to greatly influence the resilience of parents. This is because the lack of financial resources made it difficult to meet all the needs of the ill child, the needs of other family members and their other children. A contributing factor to some of the financial difficulties faced by the Saudi families was that some of the mothers lost their jobs as a result of their child's illness, which stemmed from missed workdays or their employer knowing that they would be taking leave of absence. These findings from the interviews were also supported by the results from the demographic survey results, where only 56 per cent ($N = 68$) were employed.

Financial burdens associated with raising a child with chronic illness can have negative effects on families and cause a high level of stress, not only for the parents, but for all family members (Freedman & Boyer, 2000; Parish & Cloud, 2006). Block and colleagues (2002) reported that families with chronically ill children may be likely to face high levels of stress associated with adversities. Families with low income, higher

unemployment rates and lower levels of education are even more prone to stress-related adversity.

The literature review observed similar findings, with many studies attributing income and financial instability as main factors affecting resilience (Haimour & Abu-Hawwash, 2007; Kilmer et al., 2008; Knestrict & Kuchey, 2009; Liu et al., 2007; Mohammed et al., 2013; Seltzer et al., 2011; Wyman et al., 1999; Zashikhina & Hagglof, 2009). Knestrict and Kuchey (2009) attested that the family's socioeconomic status had a significant effect on their resilience, as the financial burden of caring for children with special needs was a great stressor. Zashikhina and Hagglof (2009) also found that respondents in lower socioeconomic brackets had significantly worse family functioning, as their financial difficulties hampered their coping abilities. Haimour and Abu-Hawwash (2007) explained that the financial difficulty associated with the necessities of caring for their ill children (e.g., check-ups and therapy sessions) contributed to the lower levels of resilience among affected families. The low levels of family resilience also stemmed from feelings of pressure and anxiety, as most of the responding parents had the difficult task of caring for their child, often while making a living (Liu et al., 2007).

The lack of education also predicted high stress and low QOL ($p < .001$). The educational levels of the parents themselves were also observed to be a significant predictor of resilience. This is because educated parents were more likely to have higher levels of income, as well as the resources to successfully deal with their problems, such as seeking social support and obtaining information about their child's condition.

Similar findings were found in other studies (Liu et al., 2007; Rayner & Moore, 2007; Seltzer et al., 2011; Zashikhina & Hagglof, 2009). However, this will be further expounded on in Sections 7.2.2 and 7.2.3, as the level of the mothers' education in this study was heavily related to the level of knowledge they had about their child's condition and the level of social support they sought.

7.2.2 Factors related to caregiving.

Mothers were not only caring for their ill children; they were also taking care of their other family members, as well as fulfilling other responsibilities (as a housewife or as an employee). According to these mothers, another important aspect found to significantly affect resilience in Saudi families were related to caregiving. More specifically, those factors that negatively affected resilience were: the severity of the illness of the sick child and the level of knowledge the mothers had regarding their child's condition. The first was a recurring theme, based on the quantitative surveys, as there was a significant correlation found between stress and adversity and duration of illness ($p < .001$). The second was a common response from the mothers in the qualitative interviews. From the data it was clear that by having everything explained to the mother made them feel more positive about their child and gave them hope that things will be better. However, mothers commented that they would have liked more information.

In the quantitative analysis, parents provided information on the age of onset of illness, amount of time spent in caring for the child, and the daily activities of the children with chronic illnesses. All children in this study had illnesses that were long

term, requiring significant care, and could not be permanently cured by current medical treatment. Nearly half of the children (48 per cent) had an age of onset of one to two years, and an additional 22 per cent of the children suffered a chronic illness from birth. Almost half of the children (43 per cent) required continuous care, yet the majority of the parents (75 per cent) indicated that they spent time daily with their immediate family.

The quantitative analysis also revealed significant associations between stress and adversity and duration of illness ($p < .001$). Moreover, the variable of the number of sick children in family demonstrated a nearly significant result ($p = .06$), suggesting a particular effect on stress and adversity. Twenty-three per cent of respondents reported having more than one child suffering from a chronic illness (2–5 children).

Aside from their ill child (or children), the respondents also had their other children to care for. These participants reported having between one and six children, with the majority of parents having more than one child (71 per cent). It is also worth noting that one of the commonly recurring responses of the mothers in the qualitative investigation included problems in dealing with their other children. For instance, Omm Hassan said, 'It's really hard to take care of all children while you are giving all the attention to your sick child'. Participants also commented that they worried about their other children which may have contributed to their stress.

Studies from the literature review investigated families with only one child affected by a chronic illness: these empirical studies cited the severity of the condition as a major factor that affected resilience (Gerhardt et al., 2003; Haimour & Abu-

Hawwash, 2012; Kilmer et al., 2008; Motamedi et al., 2007; Seltzer et al., 2011). The study of Seltzer et al. (2011) in particular, found that parents whose children suffered from developmental disabilities were observed to have lower rates of employment, larger size families, and lower levels of social participation. These negative effects were comparatively less grave than those observed in the parents of children suffering from more severe conditions, such as mental health disorders. These parents were more likely to suffer from health conditions and depression (Seltzer et al., 2011). Similarly, Haimour and Abu-Hawwash (2012) observed the same findings in their study, as the QOL scores of respondent families varied according to the type of condition the child suffered from. This study found that families of children with learning disabilities had the highest QOL scores (followed by those who suffered from physical disabilities) than those with intellectual disability, with families of children with autism garnering the lowest QOL scores (with most having negative scores).

Another factor related to caregiving was the level of knowledge of the mother regarding their child's condition. The majority of the women participating in this study had the main responsibility of caring for their children, because of the nature of female roles in Saudi Arabia (Ali, Mahmood, Moel, Hudson & Leathers, 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish, Zumla, Al-Hakeem, Al-Rabeeah & Stephens, 2013). Women are generally viewed as the primary caregivers with child-rearing responsibilities, and a mother is usually the parent tasked with taking care of the children during sickness. The father's responsibility is to provide financially for their families (Baghdadi, 2011; Elamin & Omair, 2010; Flynn, 2011).

The mothers in this study stated that it was important for them to be informed in terms of understanding the illness of their child, as well as providing adequate care for them. From the data, some mothers expressed the negative emotions they felt when their child's condition was not clear to her. Mothers could not always understand what the doctors told them about their child's condition and were shocked by the initial dangerous. In contrast, other mothers commented that the information they received was clear and contributed greatly to her resilience. These mothers in this study commented that they wanted to be properly trained (by nurses) on the specific operational aspects of home health care after the child was discharged from the hospital. Aside from this, they also expressed that they wanted to receive constant updates on their child's condition to monitor their progress once they got out of the hospital. This was important not only because hands-on assistance from medical staff would be limited, but also because educating them on the care of their child enhanced their skills and confidence in caring for their child at home (Lukemeyer et al., 2000). Unfortunately, this information was not always forthcoming for all mothers. Some mothers commented that they had not been informed about the home health care or social workers from the hospital staff but instead heard about this from other parents in the hospital. This then had a negative impact on the mothers and could have easily been resolved.

The literature review discussed the contribution of knowledge to family resilience. Mohammed et al.'s (2013) study found that information and knowledge about the condition of a chronically ill child was a significant contributing factor to resilience. Many of the respondents in Mohammed et al.'s (2013) study verbalised feelings of

anxiety, stress and fear that they regularly dealt with, due to the difficulties and uncertainties of having a child suffering from a congenital anomaly or chronic illness.

However, having an adequate amount of knowledge regarding their child's condition was found to help them and their families become resilient. Their increased knowledge about the condition (obtained from physicians and health care professionals) allowed them to take care of their child more effectively, lessening their doubt about their child's comfort and overall well being. The knowledge they acquired about how congenital anomalies developed in children also pushed them to seek proper health care for the rest of their family (Mohammed et al., 2013).

7.2.3 Level of support.

A crucial factor found to be significantly associated with the level of resilience among respondents was the level of support they received, whether it was emotional or social. This support came from a variety of individuals: their spouses, children, extended family members, nurses, neighbours, friends and even support groups.

Additionally, based on the quantitative findings in this research study, 60 per cent of the Saudi mothers stated that they received respite help from family and or friends, 25 per cent reported receiving help from multiple sources (including not only family and friends, but also government associations and the hospital), and finally, 18 per cent of the participants indicated that they were not receiving help. The qualitative interviews revealed several factors that were the cause of mostly all respondent mothers experiencing low levels of resilience. These factors included the lack of social support, as well as support from their husbands. The lack of social support was described by

mothers who commented that no health professionals took care of them, asked them how they felt, or if they needed any help or support or even listened to them to see what they wanted. Mothers commented that they felt isolated at times. In contrast, the nurses behind that their role was to provide this support to the mothers. With regards to the lack of support from their husbands, mothers expressed that they would have appreciated more support their husbands. There was acknowledgement that husbands work and also felt the pressure and stress of having an ill child but still did not help or support the mother and each other through this.

The literature review clearly indicated that parents often found themselves socially isolated when they had a child with a chronic illness (Brown et al., 2008; Chiou & Hsieh, 2008; Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009). The higher level of support for parents in this study could possibly be associated with high levels of resources, such as satisfactory income and high education levels (Babcock & Laschever, 2009; Lusardi, 2008; Lusardi, 2008a). The higher the educational level the more likely the parent has the ability and confidence to be proactive in seeking out support (Babcock & Laschever, 2009; Lusardi, 2008; Lusardi, 2008a). According to Babcock and Laschever (2008), when women are more informed and confident about their needs (whether personal, financial or professional), they are more likely to ask for support or opportunities to attain these needs. Mothers expressed in the interviews that they felt relieved when they talked to other mothers who had sick children and were able to share their same feelings and concerns. These mothers shared a special connection as they listened to and support each other. Similarly, mother expressed that other family

members, such as their husband, brother and sister were very helpful in calling and visiting them as well as taking care of the other children whenever it was required. The nurses agreed that providing the facilities for other family members to visit in hospital was important.

The studies reviewed in the literature review confirmed the findings attributing emotional and social support from various sources to the level of resilience of families with a child suffering from a chronic illness (Bellin et al., 2008; Cloutier et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Hamall et al., 2014; Kheir et al., 2012; Knestrict & Kuchey, 2009; Lee et al., 2004; Liu et al., 2007; Rayner & Moore, 2007; Seltzer et al., 2011; Wyman et al., 1999). For instance, in terms of emotional support, Gerhardt et al.'s (2003) study found that the level of emotional support from the spouse and family members was observed to have a significant effect on resilience levels of mothers caring for their children who had juvenile rheumatoid arthritis (JRA). These positive attitudes and relationships mitigated the stress, anxiety and exhaustion felt by the parents as they cared for their children suffering from JRA. Likewise, Bellin et al. (2008) also observed similar findings with siblings of children suffering from spina bifida (SB). Their relationship with other family members was of great assistance to developing resilient attitudes among these children. Parents, grandparents, and even other siblings helped these respondents cope, through acts like answering their questions about their siblings' condition, providing comfort, and maintaining harmony in the family. Similarly, Hamall et al. (2014) observed (through an intervention programme called 'Child Illness and Resilience Program' or CHiRP) that effective resilience

strategies or methods were the ones that involved all family members. Their friendships also helped them develop resilient behaviours (Bellin et al., 2008). Aside from the emotional support parents received from their friends, these relationships also allowed mothers the opportunity to temporarily forget about their immediate worries and problems.

Additionally, Liu et al. (2007) explained that parents who acted as the caregivers of their child suffering from a chronic illness often felt lonely or depressed, because they were often alone in fulfilling this responsibility and did not have opportunities for leisure or socialisation. The respondents in their study stated that sharing their experiences with their neighbours and friends not only helped these people understand their difficult situation, but it was also a way for them to release their frustrations. Kheir et al. (2012) further elaborated on parent-caregivers in their study conducted in Qatar. They found that support from family members and those from support groups they joined helped these parents in three ways. First, the presence of other individuals allowed them to temporarily forget about their problems, providing a certain amount of relief (most commonly through prayer). Second, the support they received often helped with understanding the many uncertainties they had about their child's condition (e.g., how they will manage on their own in the future), thereby reducing their worries and anxieties. A third benefit was that the people who supported them (most especially other family members) also helped them perform their responsibilities as their child's caregiver.

7.3 Relationships Between Family Resilience, Stress and Chronic

Illness

This section will explore the second research question, ‘What are the relationships between family resilience and the chronic illness of a sick child?’ The quantitative findings revealed the interrelationships among these factors. The results of the quantitative analysis revealed significant correlations between QOL score and GSE ($p < .001$); between QOL and the SSQ scores ($p < .001$); between QOL and stress and adversity ($p = .02$); between GSE and SSQ ($p < .001$); between stress and adversity and duration of illness ($p < .001$); and between stress and adversity and family time in caring activities ($p < .001$). In addition, a nearly significant result was found between GSE and stress and adversity ($p = .06$).

It can be interpreted from these correlations that the chronic illness (as well as its aspects, such as the severity or length of illness) produces great stress in these families. In addition, the corresponding stress from the chronic illness may be a significant fact to how families cope and their levels of resilience. The qualitative findings are also in line with these findings. Mothers expressed in the data that they were concerned about how they would deal with having a child with a chronic illness and were needless to say, experiencing a range of emotions from being in denial, angry, fearful and upset.

7.3.1 Effect of chronic illness on stress.

As mentioned earlier, in Saudi Arabia, chronic illness is the most diagnosed type of illness among Saudi children annually (Al-Qurashi et al., 2008; Ng, Zaghloul, Ali, Harrison & Popkin, 2011). In this current study, 92 per cent of mothers of chronically ill

children were aged between 22 and 42 years. The majority of the mothers participating in this study had the responsibility of caring for their children, because of the nature of the female role in Saudi Arabia (Ali et al., 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish et al., 2013). Women are generally viewed as the primary caregivers for their sick children (Baghdadi, 2011; Elamin & Omair, 2010; Flynn, 2011).

Saudi women normally face many tasks as they perform the responsibility of caring for their chronically ill child. Strohm (2002) presented an overwhelming list of the many factors that combined to increase parental stress in families with a chronically ill child. These factors included: juggling appointments, combating exhaustion, pressure on the marital relationship and on maintaining relationships with other children. For instance, mothers commented that they had problems dealing with their other children because they are spending so much time with the sick child and not as a family. These emotions are also accompanied by fear for their ill child, for themselves and for their family. Mothers also experienced that they were anxious about their family. Parents also worry about the pain of medical procedures on their ill child and they worry about the impact of the illness on the sick child's development. Among parents' major concerns are the effects of their child's illness on the rest of the family. Other major concerns include visions of their caregiving role extending indefinitely; feelings of anger, anxiety, guilt; and the need to give up work. Medical costs add considerable monetary strain to the family's expenses in addition to the ongoing stress of day-to-day care for a child with a chronic illness, which can be physically and emotionally overwhelming. In contrast, the nurses commented about the range of financial assistance that the

government and hospital gave them. Even negotiating with service providers who are there to provide assistance to the family can be confusing and exhausting (Strohm, 2002).

Based on the findings in this current study, there were several common causes of stress among the respondents. The first was the fact that the hospital allowed only the mother to stay with the child, which resulted in a considerable amount of stress, due to the mother being alone and without emotional support. In addition, mothers were also left to deal with most (if not, all) of the responsibility of caring for their ill child. A second significant stressor identified from the data was the language barrier between the nurses and patients/patient families. This language barrier was connected to two related problems. The first was that information about the condition of the child may not easily be communicated, and as such, may cause additional worries or anxieties. Secondly, the nurses tend to be expatriates and not Arabic speaking, like the families. The language barrier may also reduce the relationship between the patients' families and the hospital staff, preventing any genial relationship or emotional support to occur. A third major cause of stress was that the mother worried about her other responsibilities outside of caring for her ill child, such as her other children who were at home, especially as her husband was working.

Similarly, the literature review (Aldosari & Pufpaff, 2014; Cloutier et al., 2002; Gerhardt et al., 2003; Haimour & Abu- Hawwash, 2012; Liu et al., 2007; Motamedi et al., 2007; Rayner & Moore, 2007; Seltzer et al., 2011) provided information on effects of the relationship between chronic illness and stress, as in this study. For instance,

Gerhardt et al. (2003) observed that respondent mothers of chronically ill children were shown to have significantly higher SCL-90-R scores, (a self-report inventory of psychological symptoms to assess parental distress) compared with a control group of mothers. Likewise, Cloutier et al. (2002) identified the effect of having and caring for a chronically ill child on the stress levels of 32 Canadian couples who underwent emotionally focused therapy to relieve their marital problems. In a study by Rayner and Moore (2007), parents of chronically ill children were more significantly stressed due to the difficult behaviour of their ill children and the high demands for caring for them. A much worse case was observed in the research of Motamedi et al. (2007), which observed varying degrees of depression (from mild to severe) among the mothers of chronically ill children. The overall QOL was also hampered in similar families, primarily due to having to care for their disabled children or worrying about how they would function without their parents (Haimour & Abu-Hawwash, 2012). Besides, Aldosari and Pufpaff (2014) found that the lives of mothers of chronically ill children outside their family were restricted. The mothers perceived they lacked competence, which contributed to their high stress levels.

7.3.2 Effect of chronic illness and stress on family resilience.

As stated previously, the results of the quantitative analysis provided significant correlations between QOL and GSE, QOL and SSQ, and GSE and SSQ. Significant correlations were also found between stress and adversity and duration of illness ($p < .001$); as well as between stress and adversity and family time in caring activities ($p < .001$). In addition, a nearly significant result was found between GSE and stress and

adversity ($p = .06$). The findings from the qualitative analysis also confirm these observations, giving evidence for the significant effects of chronic illness and stress on resilience. Similarly, the interviewees mentioned that the duration (as well as the severity) of their child's illness was a big problem, because this made them think that recovery was not plausible and that maybe their child will die. The mothers also mentioned many difficulties related to not being able to adequately fulfill their roles as a mother (to their other children), wife, and homemaker. These also caused great stress for many of the respondents. The fact that the mother was spending her time being with her sick child means that her relationship with the rest of the family can be a little strained. Interestingly, the nurses commented that their role was to encourage the mothers to go home and care for their family. There was no indication for the data whether the mothers heeded that advice or not.

Similar to the quantitative data obtained, the qualitative interviews also saw how the level of social support affected the resilience of the respondents. A commonly recurring observation among the mothers in this study was that the lack of support from the people around them led to lower levels of resilience. Saudi mothers most commonly relied on their own family and friends for support, although some of the respondents reported receiving no form of support whatsoever. Previous research has often found parents to be socially isolated when they have a child with a chronic illness, and this adds significantly to their stress and anxiety (Brown et al., 2008; Chiou & Hsieh, 2008; Kratz et al. 2009). Likewise, Arab women have learned to hide their feelings and pretend that they are healthy, especially when they have any disease that might affect

their social life. According to studies by Goldblatt, Cohen, Azaiza and Manassa (2013) as well as Azaiza and Cohen (2008), the way Arab women think is very common because these women who are also mothers are expected to be strong and resilient for their families. The women's ascribed role is that of the primary caregiver (Ali et al., 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish et al., 2013). Any weakness, whether perceived or actual, must be hidden for the sake of the family. These women learn to cope with their problems, projecting an image of selfless fortitude by being at the service of their family (Ali et al., 2008; Baghdadi, 2011; Elamin & Omair, 2010; Memish et al., 2013). This strong and resilient portrayed by the mothers may have been the reason why the nurses did not ask them if they were alright. To the nurses, therefore, these mothers came across as being resilient.

In addition, Arab women are very suspicious of allowing anyone to interview them or even participate in focus groups (Parasuraman, Cantrick-Brooks & Shareia, 2005). For instance, some mothers refused to allow the use of the audio tape recorder during the interview and asked the researcher to record the interview by note taking only, due to both the sensitivity of the situation and cultural issues (Parasuraman et al., 2005). Recording interviews may be acceptable and common in Western culture. This appeared to be more of a problem due to cultural differences between Africa, Asia and developed countries (Parasuraman et al., 2005).

In this current study, whenever a respondent was faced with a stressor, people moved closer to religion to overcome this problem. Several interviewed mothers insisted that any disease was sent by God to examine people's beliefs and that God would give

them strength to deal with this. Mothers also attested that only God can cure the condition, and this can come true through prayer and by performing religious practices. Social and cultural characteristics may be involved in how the reaction to a stressor is manifested (Padilla & Perez, 2003). For example, depression may be a more typical outcome or expression of stress among women, while abuse of alcohol or violent acts may be more characteristic among men (Padilla & Perez, 2003). As such, females may often resort to internalising their reactions or responses to stressors (McCabe et al., 2008; Pellegrini & Scandura, 2008). Religion or prayer is one of the most common ways these women deal with adversity in a positive way (McCabe et al., 2008; Pellegrini & Scandura, 2008).

Further, studies from the literature review observed the significant effect of stress on family resilience (Gerhardt et al., 2003; Kilmer et al., 2008; Seltzer et al., 2011). For instance, Seltzer et al. (2011) observed lower levels of resilience among families of children suffering from developmental disabilities in Wisconsin, USA. These were manifested through lower employment rates, a larger family size, and lower levels of social participation (Seltzer et al., 2011). Additionally, Kilmer et al. (2008) studied siblings of children suffering from severe emotional disturbances (SED) to assess whether or not they were at risk of developing the same condition. They found that the level of resilience of the sample group was correlated to the level of stress they experienced, with a lower level of resilience (and consequently a higher level of stress) becoming a possible risk for developing SED (Kilmer et al., 2008).

Likewise, Cloutier et al. (2002) observed a similar significant relationship between stress and resilience among couples. They found that emotionally focused therapy (EFT) significantly reduced stress among couples who were having marital distress due to the illness of their child. Upon completing the EFT (and even during the follow-up interview a year after), the couples were observed to be more resilient. Zashikhina and Hagglof (2009) as well as Haimour and Abu-Hawwash (2012) also observed that stressors (such as financial troubles and the severity of the child's illness) led to poorer family functioning and resilience among northern Russian and Saudi families, respectively.

It is worth noting that high levels of resilience were found in respondents of the study of Lakhani et al. (2013). Their findings revealed that Pakistani mothers perceived that caring for a child with an intellectual disability had a positive effect on family functioning and resilience, despite the adversities they faced. The reasons they attributed for this positive perception were that family members were able to understand their life's purpose through their experiences. These mothers also expressed that family members felt happiness and fulfillment as a result of caring for their child with an intellectual disability, and it also helped keep the family closely and strongly bonded (Lakhani et al., 2013). Their experience also made them more aware about future issues, and contributed to the personal growth and maturity of all members (particularly the child's siblings). This study is worth mentioning, as it may be an indication of cultural differences between Pakistanis and Saudis, in terms of how they view chronic illnesses of family members.

7.4 Role of Paediatric Nurses

This section will answer the research question, ‘What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities associated with chronically ill children?’ The responses were obtained from both the nurses (in terms of the roles they perceived to be important) and the mothers (in terms of what they desired from their nurses). There were some similarities and differences between the mothers and nurses. The two primary roles of the nurse were hospital-provided support (during the ill child’s confinement) and home health care support (in preparation for care after discharge).

7.4.1 Hospital-provided support.

The first of two major roles that the nurses perceived as important, in terms of helping families with a chronically ill child to be resilient, is providing health services and emotional support to the Saudi mother. This is especially important, because the mother is the only person allowed to stay in the hospital with the ill child at all times.

One of the specific ways the nurses supported these mothers was to help, communicate, and monitor the health of the Saudi mother as she stayed with the child. If needed, they referred the mother to other health professional to help treat her physical health or her stress levels. Often times, the parent staying with the child who is confined at the hospital experiences anxiety and depression over the condition of their child, as well as the possible uncertainties they face in confinement (Balluffi et al., 2004). In this study, the mothers often worried about her other children at home, as she was not available to take care of them. The fact that the mothers were quite isolated from other

family members throughout the child's hospital stay may have been detrimental to their level of resilience. The hospital had short visitation hours for family members, which limited the time the mothers spent with their husband and other children.

Connected to this, the nurses also provided assistance other than medical expertise and physical care, such as emotional support. This was given not only to mothers, but also to the fathers and other family members, who were generally not allowed to stay at the hospital other than during visitation hours. The father and other relatives were only allowed to do so during limited visitation hours. This put stress on both the mother, who had no relief, and the father, who was removed from the situation and was not able to help care for their child. According to Bolton (2003), it is important that nurses assume other roles than their most explicit responsibilities (i.e., physical care) to assist the patients and their families in the best way possible. The stress and anxiety experienced by family members of a patient is significantly reduced when there is a caring and influential person (such as a nurse), who can provide for their physical, emotional and spiritual needs (Bolton, 2003).

On the other hand, the mothers' responses revealed what they expected from their nurses. Even though these mothers acknowledged the great care for the patients, they admitted there was a lack of emotional support for parents from the nurses. As they were often alone, staying with their child for a long period, some respondents often felt lonely because there was not enough initiative from the hospital or the nurses to show concern for and take care of them. Mothers commented during the interview that they would have liked to be asked if they were alright. Similarly, Björk, Wiebe and

Hallström (2005) stated that a lack of genial correspondence by the hospital staff had a significant effect on the loneliness felt by family members staying with a patient. Studies by Gabe, Olumide and Bury (2004) as well as Blue-Banning, Summers, Frankland, Nelson and Beegle (2004), both attest to the importance of a good relationship between families of patients and their physicians. Proper communication allows the latter to do their job more effectively, while the former can cope more effectively. In the absence of other family members or friends, the mothers often sought companionship and emotional support from their nurses.

As previously stated in Section 7.2.3, a significant contributor to family resilience is emotional support (Bellin et al., 2008; Cloutier et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Hamall et al., 2014; Kheir et al., 2012; Knestrict & Kuchey, 2009; Lee et al., 2004; Liu et al., 2007; Rayner & Moore, 2007; Seltzer et al., 2011; Wyman et al., 1999). In the case of this study, as the mothers were interviewed at a time when they were staying with their ill children at the hospital, they often looked to their nurses for care and support. This was especially emphasised by the fact that their other family members were only allowed to stay in the hospital during limited visitation hours.

Emotional support can help moderate levels of stress, anxiety and the exhaustion felt by the parents when they cared for their children (Gerhardt et al., 2013). Parents who care for their children may often experience feelings of solitude, because they were often alone in fulfilling this responsibility and did not have opportunities for leisure or socialisation (Liu et al., 2007). Having other people around may allow them an

opportunity to release their stress. Further, support from, and positive relations with, other individuals (even those who may not be their family or friends) can provide relief, through simple acts like praying together or simply staying with the caregiver (Kheir et al., 2012). Nurses need to do more to support the mothers and take care of them. This may have not always been easy for some nurses, however, due to the language difficulties.

7.4.2 Parental education and home health care support.

The second of two major roles that the nurses perceived as important in terms of helping the families with a chronically ill child to be resilient was providing information about the patients. This is crucial, especially because this knowledge provides certainty to these families and it also helps the parents become more competent caregivers for their children after they have been discharged from the hospital.

Parental education, particularly informing and updating parents on their child's condition, was among the most frequently recurring responses of nurses. All interviewed nurses perceived this was one of the essential parts of their roles to support the families of the patients. It was very important to educate the parents in terms of understanding the chronic illness of their child, as well as providing adequate care for them. Aside from providing care for the ill child, it was important to properly educate parents on the specific operational aspects of home health care after the child was discharged from the hospital. In addition, a second role was that the mothers, who were the caregivers, needed to receive more information about their child's condition to monitor their children's progress once they got out of the hospital. This was essential, not only

because hands-on assistance from medical staff would be limited, but also because education enhances their skills and confidence (Lukemeyer et al., 2000). Despite this, the mothers made the comment that they wanted more information.

The literature review was able to find information that echoed the respondents' sentiments. First, the study by Mohammed et al. (2013) found that information provided by nurses to the parents about the condition of their chronically ill child (congenital anomaly in this study) was very helpful. The concrete information about the illness gave them the confidence and skill to take care of their child more effectively, mitigating their anxiety about their child's comfort and overall well being. The knowledge about how congenital anomaly developed in children as a result of the parents' reproductive health and overall wellness also pushed these parents to pursue proper health care for them and the rest of their family. The information from the nurses also benefited many respondents, who had or were considering having more children.

7.5 Role of the Saudi Health Care System

This section will address the fourth research question, 'How does the Saudi health care system assist in strengthening Saudi families when adjusting to the adversity associated with chronic health conditions?' Much like the previous section, these observations were obtained from both the nurses (in terms of the Saudi health care system services they perceived to be important) and the mothers (in terms of what they desired from the system). The three primary forms of assistance were: financial support, hospital-provided support (during the child's confinement) and home health care support (in preparation for care after discharge).

7.5.1 Financial support.

One of the most recurring themes in terms of support, from both nurses and mothers, was the financial support provided by the Saudi health care system. The services come in the form of free health care for these families, providing support for home health care after confinement, and monthly government monetary support to help take care of the child. Both groups acknowledged the importance of this form of support, because the financial burden of treating and caring for sick children adds a significant amount of worry for the parents. With the financial support, the parents do not have to struggle to make ends meet or worry about having proper access to health care. In the qualitative interviews, the mothers mentioned that subsidised health care was of great help to them. Despite this assistance the mothers were commented about financial difficulties. Similarly, studies by Waldfogel (2006) as well as Lukemeyer et al. (2000) attest not only to the benefits of such free care to the child, but also to the emotional and mental well being of their parents. Further, Lukemeyer et al. (2000) state that these benefits can lessen the hardship or burden felt by the parents as they care for their child.

The literature review observed similar observations, with many of the studies attributing low socioeconomic status and financial instability as frequent problems of families that hampered their resilience (Haimour & Abu-Hawwash, 2007; Kilmer et al., 2008; Knestrict & Kuchey, 2009; Liu et al., 2007; Mohammed et al., 2013; Seltzer et al., 2011; Wyman et al., 1999; Zashikhina & Hagglof, 2009). As previously stated, relatively lower levels of resilience from poorer families stemmed from feelings of

pressure and anxiety, as most of the responding mothers had the difficult task of caring for their child, often while making a living (Liu et al., 2007). Further, Haimour and Abu-Hawwash (2007) stated that the financial difficulty associated with caring for their ill children (through treatment sessions, costs of home care, regular doctor check-ups, and so forth) contributed to the level of resilience of the affected families.

7.5.2 Hospital-provided support.

The mothers themselves agreed with the nurses' responses, and cited that the information obtained from the medical team about the condition of their child was very helpful in their resilience. The lack of knowledge of mothers regarding their child's medical condition may have caused additional stress and anxiety. For instance, one of the mothers recounted how stressed and frustrated she felt in the interviews because no one knew what was wrong with her child despite many tests and many visits from doctors. Proper communication and partnership between doctors and parents help the latter deal with the adverse situations (Gabe et al., 2004). Trust and confidence (especially the parents' perception of physicians) is also fostered in the frequency of these parent-physician relationships, which helps families become resilient (Blue-Banning et al., 2004).

Aside from constant updates and increased knowledge about their child's condition, the mothers also cited other hospital services they received during the time of confinement. These included opportunities for visitation, providing recreation and play therapy, support from physician staff, religious support, social worker support, and support from hospital-patient relations specialist. Firstly, having visitation hours (for

fathers, siblings and other relatives) is important for the family, particularly the mothers. This gives them the opportunity to reconnect with their immediate and/or extended family. Aside from the social support they receive, these visits also provide stress relief as they get reassurance and companionship from their relatives, especially as mothers are often alone in staying with the sick child (Aljubran, 2010). Providing recreation and play therapy is also important, because of the physical and emotional benefits it provided to children. According to Kaminski, Pellino and Wish (2002) these included improved heart rates, mood and affect, as observed in the children. Seeing these also helps their mothers, as it allows them to observe a temporary yet significant improvement in their children's well being (Kaminski et al., 2002). Religious support, as mentioned previously, helped mothers become resilient as they entrusted their problems, fears and worries to God (Chiedozi, El-Hag & Kollur, 2003; Doumit, El Saghir, Abu-Saad, Kelley & Nassar, 2010; 2010; Fischer, Ai, Aydin, Frey & Haslam, 2010; Nabolsi & Carson, 2011; Salman & Zoucha, 2010). The support provided by hospital employees, such as social workers, physician staff, and hospital-patient relations specialists (especially with regards to home health care), provided skills and knowledge to the mothers that could be of significant help in caring for ill children at home, even without professionals.

These findings echoed those in previous sections of this chapter (connected to parental education and social/emotional support), as well as the study by Mohammed et al. (2013). These studies determined that the level of knowledge of parents regarding their child's condition (primarily obtained from their physicians) helped minimise stress

and improve their resilience, because they were more equipped to care for the patient. This also gave them the opportunity to seek proper health care for themselves and their entire family.

7.5.3 Home health care support.

Aside from access to health care and hospital assistance, the Saudi health care system also provided extended care treatment or education for family caregivers, as observed from the recurring responses from the nurses. Nurses mentioned the importance of the social workers who coordinated the discharge needs of the family and well as ensuring the mother received information and the nurse may equipment to help care for their child at home. These nurses observed that teaching parents (particularly mothers) about how to properly care for the child at home increases their skills and capabilities. In addition, it also helps boost their confidence, which reduces the stress and worries experienced by the caregiver. Educating parents also provides them with the autonomy to make decisions on their own, without much consultation from members of the physician team (Lukemeyer et al., 2000).

The mothers' responses in the qualitative interviews were also in line with these assessments. Mothers attested that the home health care referrals from hospitals and the extended treatment at home were crucial in helping them become more resilient. Aside from the previously aforementioned reasons (strengthening skills and confidence), these home health care supports from the Saudi health system were very convenient for the mothers. This was especially true for those who had other children to look after and other responsibilities (such as jobs and/or household chores) to fulfill. The extension of

the treatment of the ill child at home also expediently provided the necessary medications and equipment.

Despite the Saudi health care system providing education and home health care support to parents, some respondents were not aware of these services and others still needed information to support them in caring for their children at home. Other than equipping them with the skills and capabilities to do so, the mothers also wanted the physicians or social workers to conduct home visits to provide them with further assistance. In addition, another support desired by the mothers was long term emotional support for other family members, such as the father and siblings. Emotional support for other family members was identified as being important because having a sick child affected the dynamics of the whole family, creating added stress. The need for support is especially for the siblings of the ill children, most of whom are young children or adolescents (Hemmelgarn, Glisson & Dukes, 2001). For these siblings, these adverse and emotionally taxing experiences may take a toll on their well being and psychological development (Barrera, Fleming & Khan, 2004). These forms of support can prepare them for the difficulties that are part of these experiences, and help them adjust accordingly (Murray, 1999).

These findings were found to be similar in the studies evaluated in the literature review (Bellin et al., 2008; Cloutier et al., 2002; Gerhardt et al., 2003; Greeff et al., 2006; Hamall et al., 2014; Kheir et al., 2012; Knestrict & Kuchey, 2009; Lee et al., 2004; Liu et al., 2007; Rayner & Moore, 2007; Seltzer et al., 2011; Wyman et al., 1999). For instance, Hamall et al. (2014) particularly emphasised the importance of extending

hospital-based intervention programmes to the homes of affected families. The researchers attested that the full involvement of the family members in the intervention and the extended period of time during which it was implemented were key success factors that helped foster resilience (Hamall et al., 2014). Emotional and social support were also major ways families could become more resilient, despite the adversities they faced, particularly through the care and understanding provided by the people around them (even non-family members). The support was a positive factor that mitigated the stress, anxiety and exhaustion felt by parents as they cared for their children (Gerhardt et al., 2003). The mothers relationships with supportive family and friends also helped them develop resilient behaviours, because it helped them forget about their problems and release their frustration temporarily (Bellin et al., 2008; Liu et al., 2007). Further, knowing that someone was present to help them reduced the stress of the mothers, many of whom had responsibilities other than caring for their ill child (Kheir et al., 2012).

7.6 Factors that Contribute to Resilience in Saudi Families

The final section of this discussion chapter will address the fifth research question, ‘What factors contribute to resilience in Saudi families?’ These were categorised into three major thematic factors: social support, parental education (or knowledge) and religion.

7.6.1 Adequate emotional and social support.

As previously discussed in Sections 7.2.3, 7.4.1 and 7.5.2, sufficient amounts of emotional and social support from different sources (spouse, children, friends, neighbours, community, hospital staff, and the Saudi health care system) were

significant factors in contributing to family resilience. These forms of support are shaped by both sociocultural and religious factors that are present in Saudi society.

Based on the findings of this current study, the quantitative analysis presented a high SSQ score for the respondents. The combined mean was 5.31, which means that the individual opinion was ‘strongly agree’, representing a high SSQ result. The descriptive statistics for the SSQ score demonstrated a mean of 63.66 (*SD* 11.665) for the group of 122 participants, with a minimum score of 12 and a maximum score of 73. This also represents a high SSQ score, suggesting a relatively high level of perceived social support among the participants.

This suggested a relatively high level of perceived social support among the participants, and proves that support from one’s networks is one of the primary ways families coped. Further, the resilient group (high QOL–high stress) demonstrated the highest levels of social support, according to the analysis of variance. Visible differences were noted between these groups demonstrating high social support scores and the low QOL–high stress and low QOL–low stress groups, who demonstrated significantly lower levels of social support ($p < .001$).

In terms of GSE, similar to the results for SSQ, the resilient group (high QOL–high stress) demonstrated significantly higher mean scores of self-efficacy (GSE), similar to the scores of the high QOL–low stress group. These mean values were significantly greater than those of the less resilient low QOL–high stress, and low QOL–low stress groups ($p < .001$). Combined, these results demonstrate the significant relationship of self-efficacy beliefs and social support in supporting resilience.

The results from the qualitative interviews were also in line with these observations, as Saudi mothers most commonly relied on their own family and friends for support. The higher level of support for parents in this study could possibly be associated with high level of resources, such as good income and high education levels (Babcock & Laschever, 2009; Lusardi, 2008; Lusardi, 2008a). The higher educational level is more likely to increase the parent's ability and confidence to be more proactive in seeking out support (Babcock & Laschever, 2009; Lusardi, 2008; Lusardi, 2008a). According to Babcock and Laschever (2009), when women are more informed and confident about their needs (whether personal, financial, or professional), they are more likely to ask for support or opportunities to attain these needs. These observations from other studies were found in this sample group, based on their responses and characteristics.

Culture would also appear to explain differences in the use of social support by Saudi mothers. According to Aljubran (2010), mothers in Saudi Arabia have historically tended to have access to a greater array of institutional support, due to their lower feelings of stigma and larger support networks. This access is a part of their culture and may account for their greater use of the social coping resources available in that culture (Aljubran, 2010). Based on the findings in this study, the stigma of having a child suffering from chronic illness delayed the Saudi mothers from presenting and seeking help, or discussing their problem with their family members or friends, while some of them relied on family and friends for seeking support and help. One area of social

support in which this difference appears most evident is in the reliance on husbands among some Saudi Arabian mothers.

Indeed, some husbands of the 12 Saudi mothers figured prominently in their coping processes. Immediately after their child's diagnosis, husbands tended to encourage problem solving by actively participating in treatment decisions. This may be the case, despite many of these men having full time jobs. A specific example of this observation would be of Omm Hassan's husband, who encouraged her to be strong, despite the problems they faced. In addition, he was also the one asking questions and getting all the information from their physician about their child's condition. This is related to the strong patriarchal and sense of family that is part of Saudi.

The literature review observed similar observations of the importance of emotional and social support from the aforementioned sources to family resilience, because of two reasons. The first reason was that the emotional and social support involved positive attitudes and relationships, which mitigated the stress, anxiety and exhaustion felt by the parents as they cared for their children (Gerhardt et al., 2003). Moreover, families were often alone in fulfilling this responsibility and did not have opportunities for leisure or socialisation (Liu et al., 2007). Sharing their experiences with their family members, friends and even nurses not only helped other people understand their difficult situation, but it was also a way for them to release their frustrations.

A second reason was because income and financial stability was one of the major worries of these families. For instance, Knestrict and Kuchey (2009) identified

that the financial burden of caring for children with a chronic illness was a great stressor, especially to those who did not have financial stability. In addition, parents often had the difficult task of caring for their child while making a living (Liu et al., 2007). As such, any form of financial assistance from the Saudi government or the health care system took away a significant stressor, and allowed families to become more resilient.

7.6.2 Sufficient parental knowledge.

As previously discussed in Sections 7.2.2, 7.4.2 and 7.5.3, increased parental knowledge through education (primarily from nurses, hospital staff, and Saudi health care system programmes) was a significant factor in contributing to family resilience.

The mothers who were interviewed in this study stated that it was vital for them to be constantly informed in terms of understanding the illness of their child. They also needed to know the ways they could provide adequate care to their child. The mothers also wanted to be properly educated on the various necessities of home health care after their child is discharged from the hospital. In addition, they also preferred receiving constant updates on their child's condition to monitor their progress once they got out of the hospital. This is important not only because direct help from medical health professionals will be limited, but also because the increased knowledge enhanced the mothers' skills and confidence in caring for their child (Lukemeyer et al., 2000). Having an adequate amount of knowledge regarding their child's condition helped the mothers and their families become resilient, because their fears, doubts and anxieties about their child's condition were mitigated.

Similarly, the face-to-face interview with the nurses also revealed the factors they perceived to contribute to family resilience. A positive influence the nurses commonly referred to was parent education. According to them, this reduced stress, primarily as the competence and skills they were able to acquire in these sessions contributed to greater confidence in caring for their sick children. This echoed the responses of the parents summarised in the previous paragraph. Education also provided vital information on their child's condition, which reduced stress or anxiety associated with their doubts and questions (Gabe et al., 2004). This also helped ground the expectations of the parents so that they did not have false hopes, which keeps them in the right mindset. Nurses also commented to all of the support that families recorded through the government and the hospital that fathers would have contributed.

7.6.3 Religion and prayer.

In this study, the respondents' faith in God was identified by all Saudi mothers who were interviewed, to be their most effective coping strategy. Historical literature in the Arabic Islamic culture has long pointed to the importance of both visiting religious places and praying when faced with adversities in life, which may include financial trouble, marital problems and even illnesses (Chiedozi et al., 2003; Fisher et al., 2010; Nabolsi & Carson, 2011; Salman & Zoucha, 2010). The current study examined and expanded on the cultural resilience patterns of Saudi families with children suffering from chronic illness and living in Jeddah in the KSA.

Although Saudi mothers who were interviewed employed different coping patterns to deal with their stressors, they all tended to have a definitive primary coping

pattern to deal with their child's illness. For the Saudi mother respondents, their belief that God would help them and get their child through the illness was identified as the most important way to deal with their doubts. The faith expressed by these mothers was characterised by conversation-like prayers with God and a sense of God's personal direct involvement in their child's illness. The interviewed Saudi mothers reported that the coping pattern 'Pray or put your trust in God' was most commonly used. Similarly, the mothers' said that they prayed and read the Holy Qur'an to relax and be stronger. All of these mothers perceived these religious coping patterns as very effective. The majority of these mothers reported the following: praying for healing their child, visiting Islamic holy places (Makkah and Madina), or even washing their child's bodies with holy water (Zamzam).

In Arab culture, particularly Islamic culture, religion plays a very important role in peoples' lives (Banning, Hafeez, Faisal, Hassan and Zafar, 2009; Haque, 2008; Nabolsi & Carson, 2011; Padela, Killawi, Forman, DeMonner & Heisler, 2012). According to Banning et al. (2009), there are two reasons for preferring this coping strategy. The first is that devotees wholeheartedly believe that doing so will heal them or any of their afflicted family members. The second reason is the feeling that their struggle (whether physical, mental or emotional) is passed on or left to a higher power, minimising the psychological burden they experience (Banning et al., 2009).

In this research, Saudi mothers of chronically ill children also emphasised the importance of faith and prayer as a means of coping with their child's illness. Almost all indicated a fervent belief that God not only provided emotional comfort, but also

actively healed their children. As such, they pray because they believe it is effective. These mothers used religion as a means of coping, and they perceived it as an effective coping mechanism. Moreover, most of the mothers believed that their life and recovery were in God's hands. This was to such an extent that some mothers commented that they did not trust what the doctors told them but instead depending on God's healing abilities.

The respondent Saudi mothers of chronically ill children also reported having regular conversations with God. They believed that God protects them and their children, and that He would get their chronically ill child through their condition. This observation suggests a different form of empowerment or personal mastery. Such a belief may increase the individual's perception that daily stress, chronic strain and major life stresses are more manageable through an alliance with a more powerful force. This conclusion was also observed in the study of Banning et al. (2009), in which the act of entrusting one's struggles to a higher power was seen to benefit an individual. Indeed, all Saudi mothers of chronically ill children in this study would consider their faith in God as a problem focused coping strategy.

Studies from the Middle East, such as that of Mohammed et al. (2013) (that took place in Saudi Arabia and Egypt), as well as that of Kheir et al. (2012) (set in Qatar), both mentioned the importance of religion and prayer in helping families cope with their adversity. The respective respondents in these studies attributed the great help of entrusting their problems to a higher power as giving them a significant amount of relief, which they were able to do through prayer and visiting mosques. Daily prayer

sessions and regular visits to Makkah are specific elements of these practices cited by respondents (Najjar, 2010). For all of these reasons, therefore, it would appear that religion contributes greatly to resilience for the families in this study.

7.7 Summary

This chapter detailed and explained the results obtained from the two previous chapters of the study, with regards to how resilience applies to families with a child suffering from a chronic illness in Saudi Arabia. The five research questions were also answered to contextualise the concept of family resilience, with a particular focus on the respondent mothers who took part in this study.

The first research question sought to uncover the factors associated with resilience among Saudi families with chronically ill children. The results found several causes that could be classified into three main themes. The first were demographic characteristics, particularly the ages of the mothers, their educational levels, and their financial capability or income levels. The results found that resilient parents tended to be older, had higher educational levels, and had higher annual incomes. A second set of causes were associated with factors related to caregiving, such as the severity of the illness, as well as the level of information they had regarding their child's condition. The respondents who had children with more severe diseases, or those who had several children who suffered from a chronic illness, were found to be less resilient. Aside from this, the parents also acknowledged how regular updates and information from their physician team helped them become more resilient. A third set of causes was related to

the level of support the mothers received from other family members, friends, acquaintances, their physician staff, and the Saudi health care system.

The second research question observed the relationships between family resilience and the chronic illness of a sick child. The results found significant correlations between these factors. The chronic illness of a sick child had a considerable effect on stress, primarily due to the anxiety connected to worrying about the child's condition, as well as having to fulfill responsibilities associated with caring for them. The illness and the stress also had a significant effect on family resilience, as the severity and level of adversity they experienced had an affect on the manner in which they coped and how effective this was.

The third research question illustrated the roles of paediatric nurses in Saudi Arabia, with regards to assisting families to cope with the adversities associated with chronically ill children. The results found several roles that could be classified into two main themes. The first had to do with their role in terms of their help in the hospital, particularly through providing health services (to the patients as well as their mothers) and providing emotional support to the families. A second role involves providing information about their child's condition to educate the parents and help them prepare for home health care.

The fourth research question answered how the Saudi health care system assisted families to adjust to the adversity associated with chronically ill children. The results found several forms of assistance that could be classified into three main themes. The first was financial support, which greatly reduced the burden of the expenses associated

with treating and caring for the patients. The second theme involved hospital-provided support, which included regular updates from physician staff, opportunities for visitation, providing recreation and play therapy, support from physician staff, religious support, social worker support, and support from hospital-patient relations specialist. The third form of assistance was related to home health care for the patients, specifically through home health care referrals and providing pertinent information to the parents about how to do so.

The fifth research question observed what factors contributed to resilience in Saudi families. The responses were primarily classified into three main forms of coping strategies. The first was adequate emotional and social support. These were not only obtained from fellow family members and friends, but also from the physician staff and the Saudi health care system. The second was sufficient parental knowledge about the condition of the patient, which equipped these mothers with the skills and confidence to be able to care for their child. The third coping strategy that contributed to family resilience was religion and prayer, which was perceived as the mothers' most effective coping strategy, due to their belief that God would protect their child and that everything was part of His will. Entrusting their problems to God through prayer also gave them a sense of relief for the same reasons.

Following the discussion, the next chapter will conclude the present study. This chapter will consist of a review of the strengths and limitations of this study, the implications of the findings, as well as some recommendations for future research.

Chapter Eight: Conclusion

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Chapter 8 : Conclusion

8.1 Overview

This chapter concludes the thesis by addressing how this study had contributed to this particular area of research. In particular, it sought to describe and explore the concept of resilience in Saudi families with chronically ill children. The specific objectives of this study were as follows:

1. To explore and identify factors that contributing to resilience of Saudi parents when faced with the adversities of chronically ill children.
2. To explore the relationship between family resilience and a chronic illness of a sick child.
3. To investigate the type of support Saudi families receive from the health care system, visiting health care professionals, religious leaders, social and family networks.
4. To explore nurses' perspectives on the support offered by the Saudi health care system to these families.

This study sought to fulfill these objectives in the previous chapters and took the findings back to what is in the literature. In the rest of this chapter, a summary of the study findings and the strengths of the research will first be enumerated to justify the need for such a study regarding family resilience in Saudi Arabia, as well as its merits. The study's limitations will also be discussed to examine its constraints and possible

gaps that future studies may also address. By taking both into account, implications for research will be proposed, particularly for changes in policy. Afterwards, a rationale for these issues that need to be investigated in the Saudi context will be provided. The researcher will also be making recommendations with regards to what future studies can address in connection to this topic, especially since it is relatively unexplored in the current body of Saudi literature.

8.2 Summary of the Study Findings

The study comprised two phases that addressed the concept of resilience in Saudi families with chronically ill children. In addition, the method determined the approaches employed by these families to become resilient and the factors that led them to emerge even stronger in the face of adversity. In the first phase of the study, 122 Saudi parents with chronically ill children from the three hospitals in Jeddah region in Saudi Arabia were surveyed. In Phase 2, 12 Saudi mothers of chronically ill children and 15 paediatric nurses were interviewed.

In Phase 1, the results supported the model, suggesting that individuals with high stress and adversity, combined with high sense of QOL demonstrated resilience, which is affected by demographic variables as well as social support and general self-efficacy. The results of the study demonstrated the significant relationships between self-efficacy and social support on resilience.

In Phase 2 of the current study, the interviews revealed the factors perceived to reduce family stress and increase the ability to cope included parents reliance on God and prayer, and parent education and the need for effective staff communication. From

the nurses they described the support that the government and hospital provided to the families as well as the nurses role in providing emotional support.

8.3 Strengths of the Study

Based on the current published research, this study was the first to identify and explore the factors associated with resilience among Saudi families with chronically ill children in three main public hospitals in the Jeddah region, Saudi Arabia. The study was successful in that it contributed to a body of research to address gaps in the Saudi literature. One of the main strengths of the study was the fact that it was able to shed light on a relatively unexplored topic; namely, how Saudi women dealt with stress and adversity with the help of religion (Doumit et al., 2010). The research also discussed how the Saudi culture of collectivism influenced these women to resort to social support as a means of coping with their stress and adversity. The study also investigated further by providing an extensive insight on how mothers from Saudi Arabia coped with having a child suffering from a chronic illness. As observed in the literature review, there was a lack of studies that focused on resilience in the context of Saudi culture. Therefore, it was necessary for this research to provide a perspective on a concept that can apply to any individual or family, regardless of their age, gender, race/ethnicity, culture or socioeconomic status.

Another key strength of the study was its comprehensiveness, which largely contributed to the richness of findings and their implications. This was due to the use of the two concurrent cross-sectional research designs. Having both quantitative and qualitative forms of investigation led to two main benefits for the research. The first was

the fact that both methods presented varying depths of data, providing multiple perspectives in explaining how Saudi mothers coped with chronically ill children. The quantitative approach allowed the data to be easily understood and compared with previous research as it used statistics, and was also able to provide a general snapshot of the large sample. Conversely, the qualitative approach provided a more in-depth probe and explored the findings of respondents that the researcher wanted to study further. A second benefit was that multiple tests could discover which findings or statistical associations were consistent. These were particularly crucial in formulating reasonable conclusions or implications, based on the strength and/or comprehensiveness of the findings. As the topic of this research is relatively unexplored, getting confirmation through multiple methods ensured research rigour and contributed to the body of knowledge.

A final factor that can be attributed to the strength of the research was that the respondents surveyed and the concepts discussed were able to provide multiple perspectives in exploring the topic. The respondents in the qualitative portion of the study were 12 Saudi mothers who had children suffering from chronic illness and 15 paediatric nurses who provided the perspective of health professionals. Exploring the different perspectives of these two groups were especially important, as the successful communication and cooperation between parents and nurses was found to ameliorate resilience among the Saudi families in this study. The study was able to investigate both sides, particularly in terms of the information and coping support provided to the parents, and reinforced what both groups were saying. The nurses were able to state

what health services and supports were available to families. In contrast, the mothers shed light on what more they needed from their physicians, nurses, and the Saudi health care system in terms of health services and support. The investigation was also able to discover that many of the mothers were not aware of the health services available to them.

8.4 Limitations of the Study

Despite the noteworthy aspects of the study, the research also had several limitations. A main weakness of the study regarded the sample group used to represent the total population. This related to the relatively small sample size obtained from the selected hospitals, and that this was only in one city in the KSA. The problem with these two characteristics is that the findings may not be generalisable to the entire population of Saudi Arabia. In addition, the findings were based on only 122 Saudi parents for the quantitative surveys and 12 Saudi mothers, as well as 15 nurses for the qualitative interviews. These observations may not provide a complete or actual picture of the resilience of Saudi families with a chronically ill child.

The Saudi mothers who were part of the face-to-face interviews were also not from very diverse backgrounds in terms of their characteristics. More specifically, an overwhelming majority of these respondents had a sufficient level of educational attainment. As such, the researcher was not able to ascertain if this may have factored into their responses, and if the relatively similar results were caused by the fact that they had comparable backgrounds. An example is the link between the propensities to seek support from social networks and educational attainment (Babcock & Laschever, 2009;

Lusardi, 2008; Lusardi, 2008a). The finding that asking help from others was one of the most widely used coping mechanisms may have possibly been a result of the educational attainment characteristics of the respondents. Similarly, the sample respondents had an overwhelming majority of individuals who were married or fell in the age range of 22 to 32. A clear majority in this age category may have led to excessive similarities in their responses and in the statistical findings as a whole. In addition, the sample respondents of Saudi mothers who were interviewed were in the high stress and adversity and low QOL category. This shows that only one group of the classified as 'resilient' responded to the interviews. This was because these mothers thought that they would be getting help with their problems as a part of their participation in this research.

Another limitation of the study was that the data were limited to the perspective of the mothers. The fathers of chronically ill children were not able to participate in this study. This was primarily due to hospital rules that do not permit them to stay. Further, men are traditionally the breadwinners of families in Saudi Arabia (McCabe et al., 2008; Pellegrini & Scandura, 2008). It is also as essential to explore how fathers display resilience, despite having full time jobs along with their child suffering from illness. Their views on how their family displays resilience and what they do to foster such values can provide a richer or more in-depth context on the topic, which this study was not able to do. Related to this, the perspective of other members of the family, such as siblings, was also not observed in this research. Aside from the parents, it is also worth

investigating how brothers and sisters of chronically ill children handle this adverse situation, especially as most of them are young children or adolescents.

A final limitation of the study was connected to the research design, as it used a cross-sectional method. Therefore, conclusions are limited regarding the identification of patterns and processes of relationships among the variables investigated. While the results of this study revealed that the factors examined (e.g., social support and self-efficacy) were associated with resilience outcomes, no conclusions could be drawn regarding the causal relationships among these factors and family resilience. As the study investigated a relatively limited period in the lives of the Saudi families, the conclusions are a limited generalisation of their resilience.

8.5 Implications of the Findings

Based on the findings, there were several important implications. These are as follows.

There is an important need for the presence of an efficient working relationship between parents of children suffering from chronic illnesses and the health care professionals assigned to them. The Saudi health care system is perceived to support families by providing financial assistance in the form of free health care, support for home care services, and monthly financial support. Despite this, there is also a necessity for moral and emotional support for parents and other family members. In addition, a greater level of communication concerning the children's current medical status, what to expect, and how to care for the children would further support the parents' autonomy in caring for their own child. Additional support for the evolving dynamics of the family

could also be added to further address the difficulties experienced by parents and family members, such as allowing greater paternal participation in the care of the ill child while in hospital. Further information about the services available provided to the families through multiple means, such as brochures, verbally and posters, should also be added.

Factors perceived to affect family stress and ability to cope include parents' reliance on God and prayer. As consistently observed and stated in this research, religion has a significant impact on the way of thinking and acting of people in Saudi Arabia. Despite this, the inclination to turn to religion as a coping mechanism does not negate the belief of parents and families regarding the ability of medicine to cure their suffering child. Instead, prayer is used by families to entrust their fate to a higher power, which consequently reduces heavy feelings of being burdened by stress, fear and anxiety.

Aside from religion, social support was also seen as a popular coping mechanism for families who have a child suffering from chronic illness. This is not surprising, since Saudi Arabia is being a collectivist society. High levels of social support were attributed to respondents who were classified under the 'resilient' and 'positive expected' groups, both of whom had high QOL scores. Meanwhile, the opposite was true for mothers classified under 'negative expected' and 'poor copers' groups, who both had low QOL scores. They were found to have a significant lack of social support.

Moreover, characteristics such as age, level of annual family income, educational attainment, as well as the number of sick children in the family, were found to have significant effects on resilience and quality of life scores. Firstly, older mothers

were shown to be more resilient, because they were more likely to resort to social support as a coping mechanism for their problems. The level of annual income was also significant, which shows that the capability of families to finance the ill child's treatment and care greatly influences their resilience and quality of life. The educational attainment of the mothers was also a significant factor, and it has two implications. Firstly, these mothers had the capability to financially provide for their families with a stable job. Secondly, they are also more likely to know how to seek effective coping mechanisms, such as social support and information from healthcare professionals. The number of sick children in the family also affected resilience and quality of life, and this implies that the increase in the number of children with a chronic illness in the family increases their problems (e.g. hospitalization expenses, increased care responsibilities for mother).

8.6 The Need for Investigating Family Resilience in Saudi Culture

In performing cross-cultural research, it is essential to justify why it is necessary to undergo this type of investigation. The concept that is central to this study, which is the family unit, is one that varies in each culture (Patterson, 2002). These differences may include the function of the family unit, the ascribed roles of each member, and their relationships with other family members (Lee et al., 2004). This is a central point in establishing the need for investigating family resilience in the Saudi culture. The importance of this current study can be further exemplified by two reasons. The first is that there is a lack of studies focusing on resilience among Saudi families with a

chronically ill child. The second is that the significant role of culture and religion on the functioning of Saudi families is also a noteworthy feature of this study.

The paucity of literature on the resilience of Saudi families with chronically ill children necessitates that exploratory research should be performed on the topic. A thorough review of the research in the third chapter indicated that there is currently a paucity of substantial research available to undertake cross-cultural validation of the theory and concept of resilience in a Saudi context. In this field, there have been no comprehensive studies with in-depth examinations (whether quantitative or qualitative) to account for the role that sociocultural factors may have played in relation to the development of resilience in Saudi families. Aside from this, there was also a lack of articles exploring interrelationships between family resilience, stressors, and coping with the chronic illness of a child found in the Saudi Arabian context, which this research sought to address.

Another reason why it was important to perform this research in the context of Saudi Arabia was due to the unique characteristics of the country's culture. The behaviours of individuals and groups (such as families) are heavily influenced by their national culture and the Islamic religion (McCabe et al., 2008; Pellegrini & Scandura, 2008; Seccombe, 2002; Ungar, 2004). In particular, key characteristics of Saudi culture include the conservatism and collectivism of its societies (Pellegrini & Scandura, 2008). According to McCabe et al. (2008) the effects of these factors on how an individual or groups of individuals deal with adverse situations are especially apparent in Saudi Arabia. The same could also be true in other countries located in the same region (the

Middle East) or are predominantly Islamic. The essential role of the social environment in shaping how individuals and groups adapt to adverse circumstances (Ungar, 2004) is why a study such as this needed to be performed.

Resilience is a concept combining the unique traits of all individuals and family units, both social and communal, as well as the political environment. Many studies, including those of Luthar (2006), Seccombe (2002), as well as Luthar et al. (2000), have already indicated that the development of resilience is associated with vulnerable and family protective factors in a person's environment. It is important to understand that in many Middle Eastern or Islamic countries, family units and communities, as well as individuals, exist in a collectivist system (McCabe et al., 2008). Many authors such as Seccombe (2002) and Ungar (2004) have expressed the view that the development of resilience depends not only on the individual's disposition but also on other factors such as family protectiveness and cultural practices or community phenomenon. This is especially true, due to Saudi Arabia and the Middle East being predominantly Islamic (McCabe et al., 2008). The general conservativeness of the religion and its pronounced impact on these societies have shaped their general culture, as well as the individuals that are a part of them (McCabe et al., 2008). Seccombe (2002) also stated that to understand resilience in the context of these societies, researchers must pay attention to the structural differences in these societies, as well as what is acceptable in families from such cultures as stronger, more efficient, and functionally resilient during adverse situations (p. 385). Gilligan (2004) also stated that in children and youth, resilience is better defined as 'a variable quality that results from a process of continuous interactions

between a person and favourable factors in the surrounding context in any individual's life' (p. 93). Therefore, the level of resilience attained by any person or family within their own cultural context is directly associated to the quality of resources and elements available in that context for supporting resilience (Gilligan, 2004).

8.7 Recommendations for Future Research

Taking both the strengths and limitations of this study into account, there are several implications with regards to future research. Key findings from this study can also serve as a foundation for other researchers to address existing gaps that were not filled in this research study.

One of the biggest possible opportunities for future research is to continue to build on the scarce, but growing literature on Saudi Arabia's family health. This study was able to identify and explain several factors that contextualise this country. These include, but were not limited to, the country's collectivist and patriarchal society, as well as its Islamic propensities. Subsequent research can seek to prove whether these observations are consistent, or they may possibly find a society that is gradually changing due to increasing globalisation. Future research studies can also find new angles as a response to resilience of Saudi families, such as the role of educational attainment or single parent status in influencing resilience.

Future research studies may also explore other nations in the Middle East as a setting. The similarities and differences between Saudi Arabia and its neighbouring countries may be a topic of discussion. The factor of religion and Islam's effect on the cultures and practices on those who practice it may be a point of comparison.

In addition, due to religion being a popular coping mechanism in this study, based on the findings from the respondents, subsequent studies can explore the same research purpose in the context of other religions. Examples of these include, but are not limited to, Christianity, Buddhism and Hinduism. These studies could investigate the significance of each religion in the coping strategies of families with a child suffering from chronic illness. As this is a comparison between religions, the influence of the following factors may also be investigated: the presence of other or multiple religions in the country, the mandate of state religion, and the frequency that members of a family perform religious practices or worship.

Another recommendation for future research is to focus on or include fathers or siblings of the chronically ill children. The fathers were not able to participate in the study, because of hospital rules that limit their stay. These men also serve as the breadwinners of their families in Saudi Arabia (McCabe et al., 2008; Pellegrini & Scandura, 2008). It is also essential to explore how fathers display resilience despite having full-time jobs along with their child suffering from illness. Their views on how their family displays resilience and what they do to foster such values can provide a richer or more in-depth context on the topic, which this study was not able to do. Related to this, the perspective of the siblings is also worth investigating, especially since most of them are young children or adolescents.

It is also recommended that further studies consider a longitudinal research design to investigate resilience among Saudi families with a chronically ill child. Aside from adding to the growing knowledge about this topic, a longitudinal investigation

would provide stronger evidence regarding the causal relationships among the variables associated with resilience. Observing family resilience in a relatively lengthy period of time is particularly important to identify how this develops and changes throughout the duration of the child's chronic illness. Observations during crucial periods such as diagnosis, hospital confinement, recovery, hospital discharge, and home care may yield varying findings. These may add valuable and rich information to the results of this current study.

8.7.1 Recommendations for practice.

This study was conducted in paediatric wards at three Saudi Arabian hospitals. The results can be considered to support the concept of resilience and the coping patterns of Saudi families who have chronically ill children in the KSA, and the countries around it with similar cultural contexts. By understanding the results, nurses can use the results to make future plans for improving their own knowledge about stress, coping and resilience. They can provide emotional support through the interventions of social workers, provide physical and emotional support for mothers and fathers of chronically ill children, provide health information about the child's condition through brochures that are easy to read and understand, and educational programmes that focus on providing knowledge and skills in relation to the care of their child's illness, and set meetings to initiate support groups among mothers of children with similar health condition so they can share and help each other deal with the situation. Additionally, nurses can bring the study results to their meetings with hospital administrators, as

evidence to induce desirable changes that aim at improving the quality of nursing care to families of chronically ill children.

8.7.2 Recommendations for education.

Academics may use the results of this study and incooperate them in their teaching strategic plans. Educators may consider teaching about the need for emotional support in the nursing curriculum. This could be a main component of undergraduate nursing programmes, to prepare future nurses for providing culturally competent nursing care for families with chronically ill children. This includes in-service education and orientation.

To resolve language barriers while communicating with families of chronically ill children, in-service education programmes must be designed by the nursing continuing education teams to incorporate in their educational seminars to teach expatriate nurses the local Saudi Arabic language. If this is not possible, it may be beneficial to recruit nurses from surrounding countries who are proficient in the Arabic language. Further education is required to help expatriate nurses understand the local 'slang' language that most Saudi use in their daily communication.

Another important issue nursing educators should consider when designing the nursing curricula and educational programmes is the importance of culturally sensitive practice. The educational programmes should include courses or topics with an emphasis on teaching nurses how to provide nursing care to diverse communities.

8.8 Conclusion

It is extremely difficult having a child suffering from a chronic illness. Aside from the financial burdens that accompany with caring for chronically ill children (Lubkin & Larsen, 2006; Lukemeyer et al., 2000); families experience, physical, mental and emotional burdens that add to their challenges (Sharpe & Rossiter, 2002; Hummelinck & Pollock, 2006). This study aimed to explore the topic of how Saudi families cope with all these challenges.

This study had four aims, and the first was to explore and identify factors that lead to the resilience of these families. The second was to observe the relationships between family resilience, stress, and coping. The third aim was to investigate the support these Saudi families receive from the health care system, visiting health care professionals, religious leaders, social, and family networks. The final aim was to explore the role of paediatric nurses' in offering support and their perspectives on the support offered by the Saudi health care system to these families.

A key feature of this study was the use of two phases in data collection: a quantitative survey given to the sample of Saudi mothers of chronically ill children, as well as a qualitative interview with a smaller sample of Saudi mothers and paediatric nurses. The quantitative investigation found a significant relationship between self-efficacy beliefs and social support with resilience. The results of this study also highlighted the importance of demographic factors, such as the age of mothers, on resilience.

Aside from these, the qualitative results reflected the fact that support from family and talking with other mothers, being informed, religion and culture were also factors that contributed to the coping strategies employed by families, given that they belong to communities with strong Saudi and Islamic influences. The families' faith in God and entrusting their problems to a higher power, provided relief from the stress they experienced. In addition, the collectivist nature of the Middle Eastern culture, which places value on families and social networks, also contributed to coping with adverse experiences.

As for the implications of the study, there is an important need for the presence of an efficient working relationship between parents of chronically ill children and the health care professionals assigned to them. The study also implicated the importance of religion and social support as coping mechanisms for these families. As such, the research recommends further investigating the topics that were explored in this research in order to build on the scarce but growing knowledge about family resilience in Saudi Arabia. These include exploring the perspective of fathers and siblings, further investigating religion as a factor in resilience as well as the Middle East as a setting, and making use of a longitudinal research design.

It is extremely difficult for parents to have a child with chronic illness. Having one ill family member significantly impacts the family system and changes its dynamics. Changes in how family members spend time with each other, how they interact, and how they expend resources can create a tremendous amount of stress. More often than not, there are significant limitations on the lives of the chronically ill children,

such as the activities that they can pursue, what they can eat or drink, and how to adapt for the rest of their lives. These limitations on the child can also affect other family members, because the condition of the ill child generally has a significant implication on the activities of the entire family. Parents and siblings may suffer from feelings of guilt, due to the impact of a child's illness on the other children, as well as the prospect that the ill child may never experience a 'normal' life. This research suggests that families strive to normalise their lives as much as they possibly can. In addition to this, it is even more important to turn to helpful forms of support to cope with the stress and adversity connected to having a chronically ill child. Based on this study, these forms of coping include seeking support from others (family and friends), religion or prayer, and seeking information about the child's disease. These strategies assist family members to cope and can help foster resilience in each individual in the family to deal with their problems in a healthy and productive manner.

This study also investigated the role and current contributions of the health professionals, particularly paediatric nurses as well as the Saudi health care system, in providing support for families to cope with their adverse situations. The nurses contributed to ease the burden of these families by addressing the many needs of family members. These included parent education, health and well being of members, proper communication with the family, and providing emotional support. As for the Saudi health care system, the most common support methods provided to families of chronically ill children included financial assistance, education for caregivers, social support, and proper information dissemination.

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Appendices

Appendix A: Ethics Committee Approval from RMIT University



26th October 2011

Nouran Essam Katooa

Dear Nouran Essam

BSEHAPP 33 – 11 KATOQA Resilience of Saudi Families with Chronically ill Children

Thank you for submitting your amended application for review.

I am pleased to inform you that the CHEAN has approved your application for a period of **2 Years** to **October 2013** and your research may now proceed.

The CHEAN would like to remind you that:

All data should be stored on University Network systems. These systems provide high levels of manageable security and data integrity, can provide secure remote access, are backed up on a regular basis and can provide Disaster Recover processes should a large scale incident occur. The use of portable devices such as CDs and memory sticks is valid for archiving; data transport where necessary and for some works in progress. The authoritative copy of all current data should reside on appropriate network systems; and the Principal Investigator is responsible for the retention and storage of the original data pertaining to the project for a minimum period of five years.

Annual reports are due during December for all research projects that have been approved by the College Human Ethics Advisory Network (CHEAN).

The necessary form can be found at: <http://www.rmit.edu.au/governance/committees/hrec>

Yours faithfully,

**Chair, Science Engineering & Health
College Human Ethics Advisory Network**

Cc: CHEAN Member: Falk Scholer School of Computer Science & IT RMIT University
Supervisor/s: Lina Shawan-Akl School of Health Sciences RMIT University
Phillip Maude School of Health Sciences RMIT University

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Appendix B: Ethics Committee Approval from the Ministry of Health in Saudi Arabia

نموذج موافقة على تسهيل مهمة بحث Research Facilitation Approval Form

Date: 22/11/2011

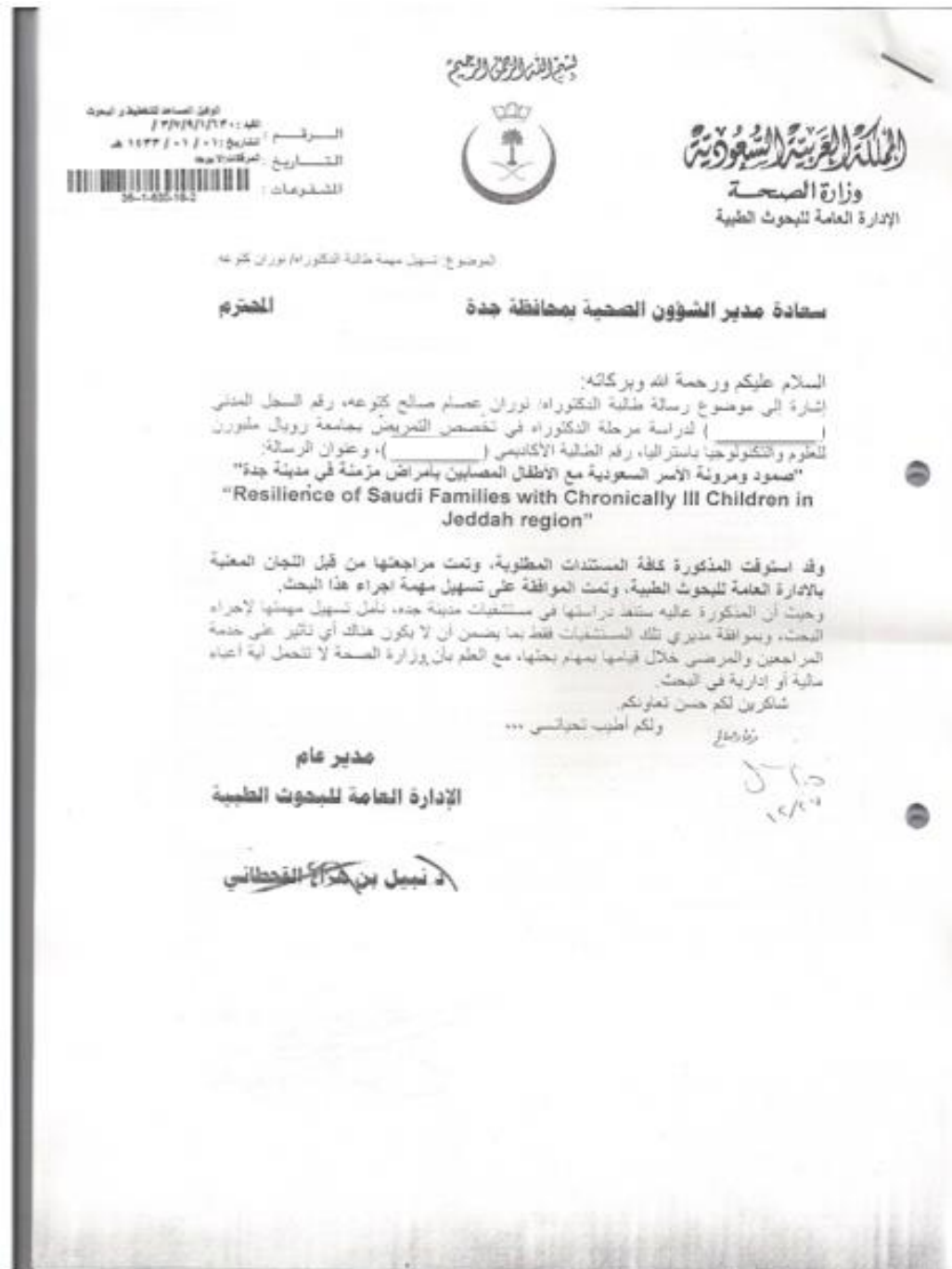
التاريخ: 1432/12/26 هـ

نوران بنت عصام بن صالح كتوعه		اسم الباحث Researcher's Name	
Resilience of Saudi Families with Chronically Ill Children in Jeddah region		عنوان الدراسة Title of the study	
Telephone/التليفون		@hotmail.com	
Melbourne		City/مدينة	
Australia		Country/البلد	
RMIT University School of Health Sciences		اسم الجامعة Name of the University	
Other <input type="checkbox"/> أخرى <input type="checkbox"/>		PhD <input checked="" type="checkbox"/> دكتوراه <input checked="" type="checkbox"/>	
MS <input type="checkbox"/> ماجستير <input type="checkbox"/>		الدرجة العلمية Scientific Degree	
Application <input checked="" type="checkbox"/>		خطاب تقديم	
Protocol <input checked="" type="checkbox"/>		بروتوكول الدراسة	
Questionnaire <input checked="" type="checkbox"/>		استمارة البحث	
Informed consent <input checked="" type="checkbox"/>		الموافقة المستنيرة	
Letter from the Univ./Affiliation <input checked="" type="checkbox"/>		خطاب من الجامعة/ جهة العمل	
Letter from Cultural attaché <input checked="" type="checkbox"/>		خطاب من الملحق الثقافي	
EC Approval <input type="checkbox"/>		موافقة لجنة الأخلاقيات	
This study aims to explore and identify factors that will lead to resilience of Saudi parents when faced with the adversities of chronically ill children. The study will also explore the role of paediatric nurses' in offering support to Saudi families as well as their perspectives on the support offered by the Saudi health care system to these families.		ملخص الموضوع Research Summary	
Approved <input checked="" type="checkbox"/> (موافق)		Not Approved <input type="checkbox"/> (غير موافق)	
To complete prerequisites <input type="checkbox"/> (لإكمال المتطلبات)		To be submitted to SC/EC <input type="checkbox"/> (يتم إرسال الطلب إلى اللجنة الطبية/ الأخلاقيات)	
Committee members		أعضاء اللجنة	
Names		الاسم	
Dr. Wafaa Saleh		د. وفاء صالح	
Dr. Ibrahim Ismail		د. إبراهيم إسماعيل	
Dr. Naseem Akhtar Qureshi		د. نسيم اختر قرشي	
Dr. Rafat Ali		د. رافت علي	
Dr. Hesham Aziz		د. هشام عزيز	

مدير عام
الإدارة العامة للبحوث الطبية

د. نبيل بن هزاع القحطاني



Appendix C: Permission from the Ministry of Health in Saudi Arabia



Appendix D: Permission from King Abdulaziz University Hospital

KINGDOM OF SAUDI ARABIA
Ministry of Higher Education
KING ABDULAZIZ UNIVERSITY
Faculty of Medicine

Ref.FM: _____
Date : / /
Encl. : _____

المملكة العربية السعودية
وزارة التعليم العالي
جامعة الملك عبد العزيز
كلية الطب

الرقم : _____
التاريخ : / / ١٤١٣ هـ
للإيفاد : _____

**UNIT OF
BIOMEDICAL ETHICS**
Research Committee

TO : Principal Investigator Ms. Nouran Essam Katooa. From : Professor H Nasrat
CO-Investigator Dr. Yagoub Bintaieb

Date : Wednesday, March 14, 2012 CC : Vice-Dean, University / Hospital Director & File & Expedite approval File

RE : " Resilience of Saudi Families with Chronically Ill Children in Jeddah Region "
(Reference No 752-12) (Survey / Questionnaire)

The above titled research/study proposal has been examined with the following enclosures:

- The study protocol.
- Data Information
- Consent Form

The REC recommended granting permission of approval to conduct the project along the following terms:

1. Annual report
2. Any amendments to the approved protocol or any element of the submitted documents should NOT be undertaken without prior re-submission to, and approval of the REC for prior approval.
3. Monitoring: the project may be subject to an audit or any other form of monitoring by the REC.
4. The PI is responsible for the storage and retention of original data of the study for a minimum period of five years.
5. The PI must inform / report REC & Sponsor by any SAE "Serious Adverse Event" within one working day

The organization & operating procedure of the KAU Faculty of Medicine - Research Ethics (Committee) are based on the Good Clinical Practice (GCP) Guidelines.

PLEASE NOTE THAT THIS APPROVAL IS VALID FOR ONE YEAR COMMENCING FROM THE DATE OF THIS LETTER.

Professor Hassan A Nasrat
Chairman of the Research Ethics Committee

Mohammed al sarree (Reference No 752-12)

ص ب ٨٠٢٠٥ ج ٢١٥٨٩
P.O. Box 80205 Jeddah 21589

فاكس ٦٤٠٠٥٩٢
Fax : 6400592

٩٨٥٢١١٦ / ٩٨٥٢٠١٣
☎ : 6952063 / 6952446

Appendix E: Permission from King Faisal Specialist Hospital and Research Centre



مستشفى الملك فيصل التخصصي ومركز الأبحاث
King Faisal Specialist Hospital & Research Centre
Gen. Org. مؤسسة عامة
Jeddah Branch - فرع جدة

NOURAN ESSAM KATOOA
Principal Investigator, IRB 2012-07
PhD Candidate, RN
RMIT University, School of Health Sciences
Melbourne Australia

DATE: 04 Jumad Al Awwal 1433
27 March 2012

REF.#: RC-J 141-33

RE: RESEARCH PROTOCOL APPROVAL
IRB 2012-07: Resilience of Saudi families with chronically ill children in Jeddah region

Dear Ms. Katooa,

Thank you for your response to the queries of the Board regarding the above-mentioned protocol (Ref # RC-135-33 dated 18 March 2012). The modifications on the English and Arabic versions of the Questionnaire were satisfactory and I am pleased to inform you that scientific and ethical approval is granted. You may now start with the conduct of your research project.

Please submit to the Board a progress report on the protocol by **26 September 2012**.

Yours sincerely,

OSMAN HAMOUR, MD
Chairman, Institutional Review Board
Research Centre
KFSH&RC(Gen.Org.) – Jeddah Branch

Tel# 667 7777 ext. 63556/62984
Fax# 6634295
E-mail: RC.jeddah@kfsrhc.edu.sa
\\msf\Documents\Person\H2



مستشفى الملك فيصل التخصصي ومركز الأبحاث
King Fahad Specialist Hospital & Research Centre
Gen. Org. مؤسسة عامة
Jeddah Branch - جدة
MBC-J04 | Fax # 82983 | Tel # 82984/82982

RECEIVED
28/3/2012

INTERNAL MEMORANDUM

TO : LOAY ABDULSAMAD, MD
Chairman, Department of Pediatrics

DATE: 05 Jumad Al Awwal 1433
28 March 2012

FROM : BAKR BIN SADIQ, MD
Acting Director, Research Centre

REF.: RC-J 143-33

SUBJECT : REQUEST FOR ASSISTANCE TO CONDUCT A SURVEY
IRB 2012-07: Resilience of Saudi families with chronically ill children in
Jeddah region

I have received a request from a Saudi student, **Ms. Nouran Katooa**, who is taking up a doctorate degree at the Royal Melbourne Institute of Technology (RMIT), College of Sciences, Engineering and Health in Australia. She would like to conduct a survey on the families of pediatric patients in our hospital as part of her thesis. The IRB has reviewed and approved the attached questionnaire that would be used and we would like to request for your approval and the assistance of your department to Ms. Katooa in the conduct of the said survey.

Your support is very much appreciated.

approved

Approved By: Loay Abdulsamad, MD

ssaMyDocuments 1433

Appendix F: Poster

Project Title:

Resilience of Saudi Families with Chronically Ill Children

عنوان مشروع البحث :

صمود و مرونة الأسر السعودية مع الأطفال المصابين بأمراض مزمنة



Investigator:

Nouran Essam Katooa (PhD Candidate- Nursing and Midwifery, School of Health Sciences, RMIT University, @student.rmit.edu.au /)

الباحثون :

السيدة نوران عصام كاتو (مرشحة للدكتوراه - علم التمريض، كلية العلوم الصحية، جامعة رويال ملبورن للمعلوم والتكنولوجيا، @student.rmit.edu.au /)

Dear participant,

You are invited to participate in a research project being conducted by Mrs. Nouran Essam Katooa. The aim of the study is to examine and identify the effects of the process of chronic illness of children, on the Saudi families' psychological and physical health, behaviour, attitudes, and how families can use their circumstances to become resilient.

عزيزي المشارك :

أنت مدعو للمشاركة في مشروع البحث الخاص به السيدة نوران عصام كاتو. الهدف من هذه الدراسة هو دراسة وتحديد الآثار المترتبة على عملية الإصابة بمرض مزمن لدى الأطفال، على الصحة النفسية والجسدية لأسرهم، و السلوك والمواقف، وكيف يمكن للأسر استخدام ظروفهم ليصبحوا أكثر مرونة وصحية.



Appendix G: Letter to Expert Nurses Panel



School of Health Sciences,
Nursing and Midwifery

GPO Box 71
Bundoora VIC 3083
Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

Letter to Expert Nurses Panel

Dear Madam/Sir,

Thank you for agreeing to assess the items of this questionnaire. The questionnaire has been designed as part of a two- concurrent phase descriptive explorative study. The first phase of this study will use this survey questionnaire to identify the factors that lead to resilience of Saudi families with chronically ill children. The second phase consists of face-to-face interviews with parents of chronically ill children to further explore the concept of resilience and the mechanisms that assist parents in adapting to adverse situations. The face-to-face interviews will also be conducted with registered paediatric nurses in order to establish whether they perceive that their institution and the health care system in general assists Saudi families in adjusting, coping and adapting to health adversities.

Project Title

Resilience of Saudi Families with Chronically Ill Children

Study Objective and Research Questions

This study aims to describe and explore the concept of resilience and the coping patterns of Saudi families who have chronically ill children. This study will also examine and identify the effects of the process of chronic illness of children, on their family psychological and physical

health, their behaviour and attitudes, and how families can use their circumstances to become resilient and healthy family. In order to establish the representativeness of the sample, a range of background information was obtained. Demographic Data, Quality of Life Scale (QOL) (Flanagan, 1982), The General Self-efficacy scale (GSE) (Schwarzer & Jerusalem, 1995) and Social Support Questionnaire (SSQ) (Sarason, Levine, Basham & Sarason, 1983) was obtained. The questionnaire will be in both Arabic and English languages. Information will be collected about the whole family (both parents and all children) as well as family access to support and respite and details about the diagnosis and care for the child with a chronic illness.

When examining the attached questionnaire, please consider the following research questions:

1. What are the factors that lead to resilience among Saudi families with chronically ill children?
2. What are the relationships between family resilience and family stress caused by the chronic illness of a sick child?
3. What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities of chronically ill children?
4. How does the Saudi health care system assist in strengthening Saudi families in adjusting to chronic health adversities?
5. What factors contribute to the resilience of Saudi families?

The Content Validity Exercise Process

You are asked to comment on the content of the survey that contains many statements measurement to assess the Saudi families of chronically ill children ability to cope with stress. This study focuses on the resilience displayed by Saudi family members when faced with the burden of chronic illness of their children.

Please read each item in the survey and examine the relevance of each item to the research questions using the below evaluation form. Please note you are only required to indicate the relevance of each item in the survey to the above five research questions.

If you have any questions regarding this research, please contact the researcher;

_____@student.rmit.edu.au or her supervisor at the following addresses _____
 _____@rmit.edu.au

Your professional opinion regarding the content of this survey is invaluable for this study and I greatly appreciate your assistance.

Yours sincerely,

Nouran Essam Katooa

PhD Candidate of Nursing - RMIT University - Bundoora

Mobile:
@student.rmit.edu.au

Content Validity Evaluation Form

Thank you for agreeing to review this instrument for content validity. We appreciate your professional and experienced judgment on developing this instrument prior to it being piloted and used for survey. Please consider each item and provide your professional judgment on the relevance of each item of the survey and the whole survey to the research questions.

The instruction for the content validity exercise are presented here:

1= Not relevant	2= Sometime relevant	3= Quite relevant	4= Very relevant
-----------------	----------------------	-------------------	------------------

Demographic section of the survey

Question Number	1	2	3	4	Recommendations and Suggestions
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					

The General Self-Efficacy Scale (GSE) Section

Question Number	1	2	3	4	Recommendations and Suggestions
16					
17					
18					
19					
20					
21					
22					
23					
24					
25					

Social Support Questionnaire Section

Question Number	1	2	3	4	Recommendations and Suggestions
26					
27					
28					
29					
30					
31					
32					
33					
34					
35					
36					
37					

Quality of Life Scale (QOL) Section

Question Number	1	2	3	4	Recommendations and Suggestions
38					
39					
40					
41					
42					
43					
44					
45					
46					
47					
48					
49					
50					
51					
52					
53					

This is the end of the evaluation form.

If you have any suggestions or recommendations regarding the instrument please do not hesitate to write it here. I appreciate your assistant to assess the content validity of this new study....

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.....

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.....

.....

.....

.....

.....

Thank you for your participation in this study

King regards,
Nouran Katooa

Appendix H: Invitation Letter to the Nursing Paediatric Wards

Letter to the Nursing Paediatric Wards



To all Paediatric nurses,

My name is Nouran Katooa. I am a PhD student at RMIT University, Melbourne, Australia. I am conducting a research study entitled

RESILIENCE OF SAUDI FAMILIES WITH CHRONICALLY ILL CHILDREN

The purpose of this study is to explore and identify factors that will lead to resilience in Saudi parents when faced with the adversities of chronically ill children and to explore the relationships among family resilience, stress, and coping within the context of having a child with a chronic illness in public hospitals in Jeddah.

Your participation will help me to establish how you assisted parents to cope and to explore your perception of how the Saudi health care system assists Saudi families in adjusting, coping and adapting to health adversities. Please respond to the invitation for the face-to-face interview placed in the ward.

Your participation is greatly appreciated.

Thank you

Sincerely,

Nouran Essam Katooa



Appendix I: Plain Language Statement for Parents



School of Health Sciences,
Nursing and Midwifery

GPO Box 71
Bundoora VIC 3083
Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

Project Title:

Resilience of Saudi Families with Chronically Ill Children

Investigator:

Nouran Essam Katooa (PhD Candidate- Nursing and Midwifery, School of Health Sciences, RMIT University, n.katooa@student.rmit.edu.au)

Supervisors:

- Associate Professor Lina Shahwan-Akl, PhD, School of Health Sciences, RMIT University, l.shahwan@rmit.edu.au Phone:
- Associate Professor Phillip Maude, PhD, School of Health Sciences, RMIT University, p.maud@rmit.edu.au Phone:

Dear participant,

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or 'plain English'. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate or not. If you have any questions about the project, please contact the investigator.

Who is involved in this research project? Why is it being conducted?

This research is being conducted by Nouran Essam Katooa as part of her studies for the award of a PhD in the Discipline of Nursing and Midwifery, RMIT University.

Why have you been approached?

You have been invited to respond to a survey questionnaire in order to assist in understanding the factors that will lead to resilience of Saudi families with chronically ill children. You may also respond to a request to participate in a face to face interview by personally contacting the researcher through email. Your participation in both the survey and the face to face interview is completely voluntary and would be greatly appreciated.

What is the project about? What are the questions being addressed?

The aim of the study is to examine and identify the effects of the process of chronic illness of children, on the Saudi families' psychological and physical health, behaviour, attitudes, and how families can use their circumstances to become resilient to adversities. It is envisaged that approximately 100-150 parents of chronically ill children will be invited to participate in the questionnaire and around 10-20 in the face to face interviews.

If I agree to participate, what will I be required to do?

After reviewing and understanding this plain language statement, you will be asked to complete a survey which will take about 30 minutes to complete. **PLEASE LOOK AT THE ATTACHED SURVEY TO CONSIDER THE TYPES OF QUESTIONS YOU WOULD BE ANSWERED.** Completing the survey will imply your consent to participate; you will be requested to return the completed survey to the researcher.

If you wish to participate in the face to face interview that will be voice recorded, you will be required to sign a consent form. The face to face interview will take around 30-60 minutes.

What are the risks or disadvantages associated with participation?

There are no risks associated with your participation in this research project. All responses will remain confidential, be reported as group data and will have no influence on the care your child is receiving.

What are the benefits associated with participation?

It is hoped that this research will provide an understanding of the factors and issues that will lead to resilience of Saudi families with chronically ill children. In order to give a better understanding, no studies have been under taken in relation to resilience of families in the Saudi Arabian context; it will be the first of its kind.

What will happen to the information I provide?

All information gathered as part of this research will be securely stored for a period of 5 years in the School of Health Sciences, RMIT University. The data can only be accessed by the researcher and supervisors. After 5 years, the data will be destroyed. The data collected will be analysed and the results will be published in academic journals or conferences without including any personal information that has the potential to identify either you or your health agency.

What are my rights as a participant?

Your participation in this research is voluntary. As a participant, you have the right to withdraw your participation at any time; have any unprocessed data withdrawn and destroyed, provided it can be reliably identified, and provided that so doing does not increase your risk and have any questions answered at any time.

Due to the nature of this data collection process, I am not obtaining written informed consent unless you elect to be interviewed.

Whom should I contact if I have any questions?

If you have any questions regarding this research, please contact the researcher; _____@student.rmit.edu.au or her supervisors at the following addresses _____@rmit.edu.au and _____@rmit.edu.au

You may also contact the following person in Saudi Arabia should you have any concerns about this research:

The General Director of General Administration of medical research

Dr. Naseem Akhtar Qureshi MD, PhD
Director, Division of Studies and Research
General Directorate of Medical Research
Sulaimania Medical Complex, Ministry Of Health,
Riyadh 11176 Kingdom of Saudi Arabia
Office:
Fax: _____

Yours Sincerely,

Nouran Essam Katooa

PhD candidate

_____@student.rmit.edu.au

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure will also be available from this address.

GOLDEN LINES
Translation office
مكتب الخطوط الذهبية للترجمة
ترخيص رقم ٥٥٢


بمديرية مكتب الخطوط الذهبية للترجمة
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ترخيص رقم ٥٥٢

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شارع صاري - هاتف : ٦٩٨٨٤٤٠ - فاكس : ٦٩٨٤٤٨٤ - غ.ش.ج : ١٢٧٠٤٦ - ص.ب ٥٣٧٦١ - جدة ٢١٥٩٣ - المملكة العربية السعودية
Sari St. - Tel. : 6988440 - Fax : 6984484 - J.C.C 127046 - P.O.Box 53761 Jeddah 21593 - Kingdom of Saudi Arabia
E-mail: AM6477@hotmail.com - www.linetranslation.com

School of Health Sciences,
Nursing and Midwifery

GPO Box 71
Bundoora VIC 3083
Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

RMIT UNIVERSITY

بهذا نشهد ان الترجمة تنقل
المعنى كاملاً وصحيحاً
We Hereby Certify That The
Attached Translation conveys The
Full And Accurate Meaning
مكتب الخطوط الذهبية للترجمة
Golden Lines Translation Office

عنوان مشروع البحث:
صمود و مرونة الأسر السعودية مع الأطفال المصابين بأمراض مزمنة.

الباحثون:
السيدة نورا عصام صالح كتوعه (مرشحة للدكتوراه - علم التمريض، كلية العلوم الصحية، جامعة RMIT University @student.rmit.edu.au)

المشرفون على البحث:

* الأستاذة البروفيسورة لينا شهبان عقل، دكتوراه، كلية العلوم الصحية، جامعة RMIT University @rmit.edu.au
تليفون:
* الأستاذ البروفيسور فيليب مود، دكتوراه، كلية العلوم الصحية، جامعة RMIT University @rmit.edu.au
تليفون:

عزيزي المشارك:
أنت مدعو للمشاركة في مشروع البحث الخاص بي و التي تجريها جامعة (RMIT University). تصف هذه الورقة معلومات مشروع البحث في لغة مبسطة. الرجاء قراءة هذه الورقة بدقة، والتأكد من فهم محتوياتها قبل أن تقرر ما إذا كنت ستشارك أم لا. إذا كان لديك أية أسئلة حول هذا المشروع، يرجى الاتصال بالباحثين أو المشرفين على هذا البحث.

من هم المشاركون في هذا المشروع البحثي؟ ولماذا يجري هذا البحث؟
هذا البحث تقوم به "السيدة نورا عصام صالح كتوعه" كجزء من دراستها لمنح شهادة الدكتوراه في علم التمريض، كلية العلوم الصحية، جامعة RMIT University.

لماذا تم الاتصال بك؟
لقد تمت دعوتك للرد على استبيان الدراسة الاستقصائية من أجل المساعدة في فهم العوامل التي تؤثر على مستوى الصمود والمرونة للأسر السعودية التي لديها أطفال مصابين بأمراض مزمنة. يمكنك أيضاً أن تستجيب لطلب للمشاركة في مقابلة شخصية وجهاً لوجه من خلال الاتصال شخصياً بالباحث عن طريق البريد الإلكتروني. إن مشاركتك في هذه الدراسة الاستقصائية والمقابلة الشخصية هو تطوعي تماماً، وستكون محل تقدير كبير.

عن ماذا هو المشروع؟ ما هي الأسئلة التي يجري تناولها؟
الهدف من هذه الدراسة هو دراسة وتحديد الآثار المترتبة على عملية الإصابة بمرض مزمن لدى الأطفال، على الصحة النفسية والجسدية لأسرهم، والسلوك والمواقف، وكيف يمكن للأسر استخدام ظروفهم لتصبحوا أكثر مرونة وصحية. ومن المتوقع أن سيبدى حوالي 100-150 أباء الأطفال المصابين بأمراض مزمنة للمشاركة في الاستبيان وحوالي 10-20 مقابلة وجهاً لوجه مع الآباء.

إذا وافقت على المشاركة، ما سوف أكون ملزماً بالقيام به؟
بعد استعراض وفهم هذا البيان بلغة واضحة، سوف يطلب منك الاستبيان الذي سوف يستغرق حوالي 30 دقيقة لإتمامه. الرجاء الإطلاع على الدراسة المرفقة للنظر في أنواع الأسئلة التي ستقوم بالإجابة عليها. إكمال الدراسة الاستقصائية يعني موافقتك على المشاركة؛ سوف يطلب منك إرجاع الدراسة المنجزة بعد إكمالها للباحث. إذا كنت ترغب في المشاركة في المقابلة الشخصية وجهاً لوجه والتي سوف تكون مسجلة صوتياً، سوف يطلب منك التوقيع على استمارة موافقة بذلك. المقابلة الشخصية سوف تستغرق حوالي 30-60 دقيقة.

ما هي المخاطر أو العيوب المرتبطة بالمشاركة؟
لا توجد مخاطر مرتبطة بمشاركتك في هذا المشروع البحثي. جميع الردود سوف تظل سرية، وإن مجموعة البيانات لن يكون لها أي تأثير على الرعاية التي يتلقاها طفلك.

ما هي الفوائد المرتبطة بالمشاركة؟
يأمل أن هذا البحث سيمنح فهم العوامل والمسائل التي تؤثر على قدرة الأسر السعودية التي لديها أطفال مصابين بأمراض مزمنة. ومن أجل إعطاء فهم أفضل، لم تجر أي دراسات تتعلق بمرونة الأسر في السياق العربي السعودي؛ سوف تكون هذه الدراسة الأولى من نوعها.

www.linetranslation.com - (01) 210 2849 - فاكس - (01) 210 4008 - هاتف - شارع العليا العام - مركز الرياض التجاري - الدور الأول - الرياض - المملكة العربية السعودية

الخطوط الذهبية سر جمه الرياض - شارع العليا العام - مركز الرصيص التجاري - الدور الأول - هاتف : ١٦٣٠٥١ (٠١) - فاكس : ١٦٣٠٧٨١٩ (٠١) - www.linetranslation.com

ماتاً سيحدث للمعلومات التي سوف أقدمها؟
جميع المعلومات التي تم جمعها كجزء من هذا البحث سيتم تخزينها بشكل آمن لمدة 5 سنوات في كلية "العلوم الصحية"، جامعة RMIT University. يمكن فقط الوصول إلى البيانات من قبل الباحثين والمشرفين. وبعد 5 سنوات، سيتم تدمير البيانات بالكامل. وسيتم تحليل البيانات التي تم جمعها وسوف تنشر النتائج في المجلات الأكاديمية أو المؤتمرات ولكن أية معلومات شخصية لن يتم التصريح بها.

ما هي حقوقكم كمشارك؟
مشارككم في هذا البحث هو طوعي. كونكم كمشارك، لنكون الحق في سحب مشاركتكم في أي وقت، وسوف يتم سحب و تدمير أية بيانات خاصة بك، شريطة أنه يمكن التعرف على أدلة موثوق بها، وبشرط أن ذلك لا يزيد من الخطر، وسوف يتم الرد على أية أسئلة في أي وقت. نظراً لطبيعة عملية جمع البيانات، لن أتمكن من الحصول على موافقة خطية ما لم تقوم بالموافقة على إجراء المقابلة الشخصية أولاً.

إذا كان لديك أي استفسار، يرجى التواصل مع الأستاذة البروفيسور لينا شهوان علل على (linas@rmit.edu.au) أو الأستاذة البروفيسور فيليب مود على (pmod@rmit.edu.au) من كلية العلوم الصحية بجامعة (RMIT University).

كما يمكنك أيضاً الاتصال في المملكة العربية السعودية إذا كان لديك أية مخاوف حول هذا البحث ب : مدير عام الإدارة العامة للبحوث الطبية، الدكتور نسيم قرشي، على (nsim@rmit.edu.au).

وفي حالة الرغبة للتقدم بشكوى حول كيفية إدارة المقابلات الشخصية، أمل الاتصال باللجنة الدائمة لأخلاقيات البحوث على العنوان التالي:

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure will also be available from this address.

مع جزيل الشكر

السنداء نوران عصام صالح كتوعه
مرشحة للدكتوراه علم التمريض، كلية العلوم الصحية، جامعة RMIT University
norah@student.rmit.edu.au

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Appendix J: Plain Language Statement for Nurses



School of Health Sciences,
Nursing and Midwifery

GPO Box 71
Bundoora VIC 3083
Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

Project Title:

Resilience of Saudi Families with Chronically Ill Children

Investigator:

Nouran Essam Katooa (PhD Candidate- Nursing and Midwifery, School of Health Sciences, RMIT University, _____@student.rmit.edu.au)

Supervisors:

- Associate Professor Lina Shahwan-Akl, PhD, School of Health Sciences, RMIT University, _____@rmit.edu.au Phone: _____
- Associate Professor Phillip Maude, PhD, School of Health Sciences, RMIT University, _____@rmit.edu.au Phone: _____

Dear participant,

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or 'plain English'. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate or not. If you have any questions about the project, please contact the investigator.

Who is involved in this research project? Why is it being conducted?

This research is being conducted by Nouran Essam Katooa as part of her studies for the award of a PhD in the Discipline of Nursing and Midwifery, RMIT University.

Why have you been approached?

You have been invited to respond to a face to face interview in order to assist in understanding the factors that will lead to resilience of Saudi families with chronically ill children. Your respond to participate in the face to face interview might be requested by personally contacting the researcher through email. Your participation in the face to face interview is completely voluntary and would be greatly appreciated.

What is the project about? What are the questions being addressed?

The aim of the study is to examine and identify the effects of the process of chronic illness of children, on their family psychological and physical health, their behaviour and attitudes, and how families can use their circumstances to become resilient and healthy family. It is envisaged that approximately 10-20 registered nurses will be invited to participate in the face to face interviews.

If I agree to participate, what will I be required to do?

After reviewing and understanding this plain language statement, you will be asked to participate in the face to face interview that will be voice recorded, you will be required to sign a consent form. The face to face interview will take around 30-60 minutes.

What are the risks or disadvantages associated with participation?

There are no risks associated with your participation in this research project. All responses will remain confidential, be reported as group data and will have no influence on your employment if you are a nurse in this hospital.

What are the benefits associated with participation?

It is hoped that this research will provide an understanding of the factors and issues that will lead to resilience of Saudi families with chronically ill children. In order to give a better understanding, no studies have been under taken in relation to resilience of families in the Saudi Arabian context; it will be the first of its kind.

What will happen to the information I provide?

All information gathered as part of this research will be securely stored for a period of 5 years in the School of Health Sciences, RMIT University. The data can only be accessed by the researcher and supervisors. After 5 years, the data will be destroyed. The data collected will be analysed and the results will be published in academic journals or conferences without including any personal information that has the potential to identify either you or your health agency.

What are my rights as a participant?

Your participation in this research is voluntary. As a participant, you have the right to withdraw your participation at any time; have any unprocessed data withdrawn and destroyed, provided it can be reliably identified, and provided that in doing so it does not increase your risk and have any questions answered at any time.

Due to the nature of this data collection process, I am not obtaining written informed consent unless you elect to be interviewed.

Whom should I contact if I have any questions?

If you have any questions regarding this research, please contact the researcher;

_____@student.rmit.edu.au or her supervisors at the following addresses
_____@rmit.edu.au and _____@rmit.edu.au

You may also contact the following person in Saudi Arabia should you have any concerns about this research:

The General Director of General Administration of medical research

Dr. Naseem Akhtar Qureshi MD, PhD

Director, Division of Studies and Research

General Directorate of Medical Research

Sulaimania Medical Complex, Ministry Of Health,

Riyadh 11176 Kingdom of Saudi Arabia

Office:

Fax:

Yours Sincerely,

Nouran Essam Katooa

PhD candidate

_____@student.rmit.edu.au

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure will also be available from this address.

Appendix K: Consent Form



School of Health Sciences,
Nursing and Midwifery

GPO Box 71
Bundoora VIC 3083
Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

Prescribed Consent Form for Persons Participating in Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

Portfolio: RMIT University "Science, Engineering and Health Sciences"
School of: Health Sciences
Name of participant: _____
Project Title: Resilience of Saudi Families with Chronically Ill Children
Name(s) of investigators: _____
(1) Mrs. Nouran Essam Katooa (PhD Candidate) Phone: _____
(2) A/Prof Lina Shahwan-Akl Phone: _____
(3) A/Prof Phillip Maude Phone: _____

- I have received a statement explaining the interview/questionnaire involved in this project.
- I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.
- I authorise the investigator or his or her assistant to interview me or administer a questionnaire.
- I acknowledge that:
 - Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
 - I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
 - The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
 - The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.
 - The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to the Saudi Ministry of Health. Any information which will identify me will not be used.

Participant's Consent

Participant: _____ Date: _____
(Signature)

Witness: _____ Date: _____
(Signature)

Where participant is under 18 years of age:

I consent to the participation of _____ in the above project.

Signature: (1) _____ (2) _____ Date: _____
(Signatures of parents or guardians)

Witness: _____ Date: _____
(Witness to signature)

Yours Sincerely,

Nouran Essam Katooa
PhD candidate

Participants should be given a photocopy of this consent form after it has been signed.

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure are available from the above address.

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Sari St. - Tel. : 6988440 - Fax : 6984484 - J.C.C 127046 - P.O.Box 53761 Jeddah 21593 - Kingdom of Saudi Arabia
E-mail: AM6477@hotmail.com - www.linetranslation.com



School of Health Sciences,
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Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

نموذج الموافقة المنصوص عليها للأشخاص الذين يشاركون في مشاريع البحوث التي تنطوي على المقابلات، الاستبيانات أو الكشف عن المعلومات الشخصية

الجامعة:	رويل ميلبورن للعلوم والتكنولوجيا
الكلية:	كلية العلوم الصحية
اسم المشارك:	
عنوان مشروع البحث:	مسعود و مروة الأسر السعودية مع الأطفال المصابين بأمراض مزمنة
أسماء الباحثين:	السيدة نورا عصام صالح كترعه (مرشحة للدكتوراه) تليفون:
(1)	الأستاذة البروفيسورة لينا شهوان علي تليفون:
(2)	الأستاذة البروفيسورة فيليب مود تليفون:
(3)	

1. أتي تلقيت رسالة دعوة للمشاركة في مقابلة شخصية/استبيان خاصة بدراسة الباحث، و أنتي أوافق على ما ذكر فيها.
2. الموافقة على المشاركة في المشروع المذكور أعلاه.
3. المعلومات سوف تستخدم لمشروع هذا البحث فقط.
4. أتي أوافق على التالي:
 - a) أتي قرأت تعليمات تعريف البحث، و أوافق على ما جاء فيها بشكل عام.
 - b) إن مشاركتي طوعية و بإمكانني الانسحاب من المشروع بدون أي التزامات تتركب على ذلك.
 - c) أنه ليس لي مصلحة مباشرة من مشروع البحث.
 - d) البيانات المسجلة سوف تعامل بسرية تامة مع عدم ذكر أي بيانات تشير إلى هوية المشارك في حالة نشر نتائج الدراسة، وستقدم تقريراً عن نتائج المشروع إلى وزارة الصحة السعودية.
 - e) أي من معلوماتي الشخصية لن تستخدم أو يفسح عنها إلا لو أعطيت ترخيص مسبق بذلك.

موافقة المشارك:

المشارك: _____ التاريخ: _____

الشاهد: _____ التاريخ: _____

موافقة المشارك فيها دون سن الـ 18 سنة:

أوافق على المشاركة في المشروع المذكور أعلاه.

المشارك: _____ التاريخ: _____

الشاهد: _____ التاريخ: _____

مع جزيل الشكر....

بهذا نشهد ان الترجمة نقلت
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السيدة نورا عصام صالح كترعه

ينبغي إعطاء المشاركين نسخة من هذا نموذج الموافقة بعد التوقيع.....
و في حالة الرغبة للتقدم بشكوى حول كيفية إدارة المقابلات الشخصية، أمل الاتصال باللجنة الدائمة لأخلاقيات البحوث على العنوان التالي:

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure are available from the above address.

Appendix L: Invitation Letter to the Parents

Letter to Parents دعوة للآباء



عزيزي المشارك:

أنا السيدة نوران عصام صالح كاتوع (مرشحة للدكتوراه) من جامعة رويال ميلبورن للتعليم والتكنولوجيا، ميلبورن، أستراليا.
عنوان مشروع البحث

صمود و مرونة الأسر السعودية مع الأطفال المصابين بأمراض مزمنة

Dear Participant,

My name is Mrs. Nouran Katooa. I am a PhD student at RMIT University, Melbourne, Australia. I am conducting a research study entitled

RESILIENCE OF SAUDI FAMILIES WITH CHRONIALLY ILL CHILDREN

الهدف من هذه الدراسة هو دراسة العوامل التي تؤثر على مستوى الصمود و المرونة للأسر السعودية التي لديها أطفال مصابين بأمراض مزمنة وتحديد الآثار المترتبة على عملية الإصابة بمرض مزمن لدى الأطفال، على الصحة النفسية والجسدية للأسر، و السلوك والمواقف، وكيف يمكن للأسر استخدام ظروفهم ليصبحوا أكثر مرونة في مستشفيات حكومية في مدينة جدة.

The aim of the study is to examine and identify the effects of the process of chronic illness of children, on the Saudi families' psychological and physical health, behaviour, attitudes, and how families can use their circumstances to become resilient to adversities in public hospitals in Jeddah.

يمكنك أيضاً أن تستجيب لطلب المشاركة في مقابلة شخصية وجها لوجه من خلال الاتصال شخصياً بالباحث عن طريق البريد الإلكتروني.

You may also respond to a request to participate in a face to face interview by personally contacting the researcher through email.

إن مشاركتك في هذه الدراسة الاستقصائية و المقابلة الشخصية هو تطوعي تماماً، وستكون محل تقدير كبير.

Your participation in both the survey and the face to face interview is completely voluntary and would be greatly appreciated.

مع جزيل الشكر،،،

السيدة نوران عصام صالح كاتوع

Thank you

Mrs. Nouran Essam Katooa



Appendix M: Questionnaire



School of Health Sciences,
Nursing and Midwifery

GPO Box 71
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Australia
Ph: +61 3 9925 7447
Fax: +61 3 9467 5286

Demographic Questionnaire

Instructions: please answer each question to your best ability. All your answers will remain confidential. With such **little** information about **Family Resilience in Saudi Arabia**, every response will help towards maintaining a successful program for Saudi families.

Thank you, Nouran Katooa

-
1. Gender
 - ☐ Male
 - ☐ Female
 2. What is your relationship to the chronically ill child?
 - ☐ Mother
 - ☐ Father
 - ☐ Grand Parent
 - ☐ other (please describe).....
 3. What is your age?
 - ☐ Less than 21
 - ☐ 22-32
 - ☐ 33-42
 - ☐ 43-52
 - ☐ above 53
 4. What is your current marital status?
 - ☐ Married
 - ☐ Widowed
 - ☐ Divorced
 5. What is your occupation?
 6. What is your total family annual income?
 - ☐ SR 24,000 – SR 35,000
 - ☐ SR 36,000 - SR 45,000
 - ☐ SR46,000 – SR 55,000
 - ☐ SR 55,000 and above

7. What is your highest level of education?

- ☐ Primary
☐ Secondary
☐ Technical
☐ Tertiary

8. How many children do you have?

9. Please complete the table below by specifying age of child and circling correct responses:

	Age	Gender	Living with you	Health
Child 1		Boy/ Girl	Yes/ No	Healthy / Sick
Child 2		Boy/ Girl	Yes/ No	Healthy / Sick
Child 3		Boy/ Girl	Yes/ No	Healthy / Sick
Child 4		Boy/ Girl	Yes/ No	Healthy / Sick
Child 5		Boy/ Girl	Yes/ No	Healthy / Sick
Child 6		Boy/ Girl	Yes/ No	Healthy / Sick
Child 7		Boy/ Girl	Yes/ No	Healthy / Sick
Child 8		Boy/ Girl	Yes/ No	Healthy / Sick
Child 9		Boy/ Girl	Yes/ No	Healthy / Sick
Child 10		Boy/ Girl	Yes/ No	Healthy / Sick
Child 11		Boy/ Girl	Yes/ No	Healthy / Sick
Child 12		Boy/ Girl	Yes/ No	Healthy / Sick

10. Does your sick child have any of the following chronic illnesses?

- ☐ Neurologic conditions (such as epilepsy)
☐ Blood diseases (such as anaemia, thalassemia)
☐ Cancer, please specify _____
☐ Respiratory diseases
☐ Cardiovascular diseases
☐ Diabetes diseases
☐ Bone and joint conditions
☐ Kidney and Urologic conditions
☐ Other, please specify _____

11. For how long has your child had the chronic illness?

- ☐ From birth
☐ 1-2 years
☐ 3-4 years
☐ Above 5 years

12. Approximately how much time each day do you spend in caring activities for your sick child?

- ☐ Less than 1 hour
☐ 2-3 hours
☐ 4-5 hours
☐ more than 6 hours
☐ continuous care

13. How often does your immediate family spend time together?

- ☐ None
- ☐ 1-2 hours/ day
- ☐ 3-4 hours/ day
- ☐ 5 and more hours/ day
- ☐ Daily
- ☐ Once a week
- ☐ 2-3 times a week
- ☐ Monthly

14. Does your family receive respite help?

- ☐ Yes
- ☐ No

15. If yes, from what sources does your family receive respite help?

- ☐ Family
- ☐ Friends
- ☐ Hospital
- ☐ Government association
- ☐ Other, please specify

The General Self-Efficacy Scale (GSE)*English version by Ralf Schwarzer & Matthias Jerusalem, 1995***Response Format**

1= Not at all true 2= Hardly true 3= Moderately true 4= Exactly true

16.	I can always manage to solve difficult problems if I try hard enough.	
17.	If someone opposes me, I can find the means and ways to get what I want.	
18.	It is easy for me to stick to my aims and accomplish my goals.	
19.	I am confident that I could deal efficiently with unexpected events.	
20.	Thanks to my resourcefulness, I know how to handle unforeseen situations.	
21.	I can solve most problems if I invest the necessary effort.	
22.	I can remain calm when facing difficulties because I can rely on my coping abilities.	
23.	When I am confronted with a problem, I can usually find several solutions.	
24.	If I am in trouble, I can usually think of a solution.	
25.	I can usually handle whatever comes my way.	

Social Support Questionnaire*Sarason, Levine, Basham, & Sarason, 1983*

	Strongly agree	Agree	Slightly agree	Slightly disagree	Disagree	Strongly disagree
26. There is a special person who is around when you are in need.						
27. There is a special person with whom you can share joys and sorrows.						
28. Your family really tries to help you.						
29. You get the emotional help and support you need from your family.						
30. You have a special person who is a real source of comfort to you.						
31. Your friends really try to help you.						
32. You can count on your friends when things go wrong.						
33. You can really talk about your problems with your family.						
34. You have friends with whom you can share your joys and sorrows.						
35. There is a special person in your life who cares about your feelings.						
36. Your family is willing to help you make decisions.						
37. You can talk about your problems with your friends.						

Quality of Life Scale (QOL)*Flanagan, 1982*

Please read each item and circle the number that best describes how satisfied you are at this time.
 Please answer each item even if you do not currently participate in an activity or have a relationship.
 You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
38. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
39. Health - being physically fit and vigorous	7	6	5	4	3	2	1
40. Relationships with parents, siblings & other relatives- communicating, visiting, helping	7	6	5	4	3	2	1
41. Having and rearing children	7	6	5	4	3	2	1
42. Close relationships with spouse or significant other	7	6	5	4	3	2	1
43. Close friends	7	6	5	4	3	2	1
44. Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
45. Participating in organizations and public affairs	7	6	5	4	3	2	1
46. Learning- attending school, improving understanding, getting additional knowledge	7	6	5	4	3	2	1
47. Understanding yourself - knowing your assets and limitations - knowing what life is about	7	6	5	4	3	2	1
48. Work - job or in home	7	6	5	4	3	2	1
49. Expressing yourself creatively	7	6	5	4	3	2	1
50. Socializing - meeting other people, doing things, parties, etc	7	6	5	4	3	2	1
51. Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
52. Participating in active recreation	7	6	5	4	3	2	1
53. Independence, doing for yourself	7	6	5	4	3	2	1

Appendix N: Nurses' Interview Questions

- ✚ How you as a nurse assist families with chronically ill children?
- ✚ Does your shift allow you time with family?
- ✚ Who do you rely on to give support to these families?
- ✚ Does the hospital provide support services, financial services, and/or family reunion with other siblings?
- ✚ Does the hospital have parks, play grounds, and/or recreation therapy to these children? Do they provide relief services to parents?
- ✚ Do Saudi families receive support from any of the following:
 - ✚ Health Care System, Health Care Professionals, Religious Leaders, Social and Family Networks
- ✚ How does paediatric nurses' offer support to Saudi families?
- ✚ How does the Saudi health care system offer support to Saudi families?
- ✚ Do Saudi parents need to learn how to deal with parental stress associated with their child's chronic illness and the stress it poses on other siblings, and why?
- ✚ How does the Saudi health care system assist Saudi families?
- ✚ What is the role of paediatric nurses in Saudi Arabia in assisting families to cope with the adversities of chronically ill children?

Appendix O: Mothers' Interview Questions



Parents Interview	مقابلة مع الوالدين
It must be very difficult to you both having a chronically sick child.	لا بد وأنكما تعانيان صعوبات جمة جراء المرض المزمن الذي أصاب ولدكما.
1/This might be stressful on you. I can appreciate how difficult this is for all and I want to ask you what does it mean to you to have a chronically ill child? How do you cope? Who helps you? How are the rest of the children coping?	1/ وربما يشكل هذا الوضع عبئا ثقيلا عليكم. وأنا أقدر تلك بكل الأحوال، ولكنني أريد أن أسألكم عنيكم سؤالا، ماذا يعني أن يكون لكما ولد مصاب بمرض مزمن؟ كيف لكما أن تستوعبا الأمر؟ من يقدم لكما يد العون؟ كيف يتعايش بقية الأولاد مع هذا الوضع؟
2/ Can you please explain to me how you felt when you heard you child is going to be chronically ill?	2/ هل يمكنكما أن توضحا لـ... كيف كان شعوركما عندما أخبرتما أن ولدكما مصاب بمرض مزمن؟
3/ Can you please explain what emotions did you go through? Were there disbelief and denial, anger, fear, grief and then acceptance? How long did it take you and your family to accept this situation?	3/ هل باستطاعتكما أن تصفا شعوركما في تلك اللحظة؟ هل كان هناك شعور لديكما بعدم التصديق أو الإنكار، أو الغضب، أو الحزن وبالتالي الوصول إلى قبول الفكرة؟ كم من الوقت استغرقتم مع بقية أفراد الأسرة حتى تقبلتم الوضع الجديد؟
4/ How do you face up or confront your child's illness?	4/ كيف تواجهان متاعب ومصاعب مرض ولدكما المزمن؟
5/ How do you make it possible to think positively about this problem?	5/ كيف تمكنتما من التفكير بشكل إيجابي للتعامل مع هذه المشكلة؟
6/ How do you feel when you think negatively or act in a negative way when dealing with your child's illness?	6/ كيف تشعران عندما تفكران بشكل سلبي أو بطريقة سلبية أثناء تعاملكما مع مرض ولدكما المزمن؟
7/How do you express or release your emotions when facing a problem?	7/ كيف تعبران أو تصرفان تحت وطأة العاطفة عند مواجهة صعوبة ما؟
8/ What do you do to help yourself feel better?	8/ ماذا تفعلان حتى تشعران بالتحسن عند ذلك؟
9/Do you have any financial, emotional, psychological difficulties because of your child's illness?	9/ هل تواجهان مصاعب مالية، أو عاطفية، أو نفسية بسبب وضع ولدكما المريض؟
10/Do you work? Do you have any problems with work hours, do they give you time out when required to be in hospital? Are they understanding? If not how do you cope?,	10/ هل أنتما موظفتان؟ هل لديكما متاعب أثناء ساعات العمل، وهل يؤذن لكما بالخروج من العمل عند الضرورة للذهاب إلى المستشفى؟ هل يفهم صاحب العمل الوضع؟ إذا لم يكن الأمر كذلك، كيف تتصرفان؟
11/How would you like to be helped by whom; work/family/relatives/friends/ government??? Please tell me if you have any of these help?	11/ كيف لئول أن تلتزم لكما المساعدة بهذا الشأن؟ ومن لود أن تكون المساعدة؟ من العمل، من الأسرة، من الأقارب، من الأصدقاء، من الحكومة؟؟ يرجى الرد على هذه الأسئلة، إذا تلتزم مساعدة من أي طرف من هؤلاء.
12/How would the situation be better if you had all these helps? How would the situation be better for other children in the household or siblings? Can you imagine this situation and tell me what would you like from your immediate community?	12/ كيف يكون الحال أفضل إذا قدمت هذه الأطراف كلها المساعدة المتشودة؟ كيف سينعكس الوضع على أهل البيت والأولاد خصوصا؟ هل تستطيعان تخيل هذا الوضع وإبلاغي فيما إذا كنتما ترغبان المساعدة من المجتمع القريب حولكما؟
13/How much you rely on supports (such as; religious leaders support) when facing this problem?	13/ ما مدى اعتمادكما على المساعدات (كالمساعدة من رجال الدين) عند مواجهة هذه المشكلة؟
14/What help would you like to have from your hospital for example?	14/ ما هو نوع المساعدة التي ترغبان بها من طرف المستشفى على سبيل المثال؟
15/It must be very difficult to you both having a chronically sick child.	15/ هل هناك أي طريقة أخرى لاستيعاب المشكلة، من ناحية الأهمية أو التفكير؟
Please answer.	يرجي الرد.

بهذا نشهد ان الترجمة تنقل
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Appendix P: Certified Translation Letter for the Questionnaire

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مكتب الخطوط الذهبية للترجمة
ترخيص رقم ٥٥٢

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بانت الترجمة الشفوية تفيد
المعنى كاملاً وصحيحاً
حتى وافصل.

Mr. Abdullah P. Al-Malki الدكتور عبد الله بن سعود المالكي

License No. : 552 ترخيص رقم ٥٥٢





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استبيان ديموغرافي

تعليمات : الرجاء الإجابة على كل سؤال على أفضل ما تتيقن. مع العلم أن كل إجاباتكم سوف تبقى سرية. مع القليل من المعلومات حول قدرة الأسرة في المملكة العربية السعودية ، وستجابتكم لهذا الاستبيان سوف تساعد على الحفاظ على برنامج ناجح للعمليات السعودية.

شکرا لکم... نوران مکتوبه

1. الجنس :

59

□ الثاني

2. ما هي علاقتك بالطفل الذي يعاني من مرض مزمن ؟

□

3

4

☐ آخری (برجی وصلہا)

3. العمر؟

☐ أقل من 2132 22 ☐42 33 ☐52 43 ☐

53 فوق □

4. الحالة الإجتماعية ؟

☐ متزوج☐ ارمل☐ مطلق

5. ما هي مهنتك؟

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استبيان توقع الكفاءة الذاتية العام

1 = لا أبداً 2 = قليل 3 = متوسط 4 = كثيراً

16.	إذا عارضني شخص ما، أستطيع إيجاد طرق ووسائل لتحقيق ما أبتغيه.
17.	أستطيع دائماً حل المشاكل الصعبة إذا أجهدت نفسي بما فيه الكفاية.
18.	يسهل علي تحقيق أهدافي و توياتي.
19.	إذا فوجئت بمواقف غير متوقعة أعرف دائماً كيف أتصرف.
20.	أعتقد بأنني قادر على معالجة المشاكل بشكل جيد حتى ولو كانت مفاجئة.
21.	أنظر إلى المصائب بنفس هادئة "برزانة" وذلك لاعتمادى دائماً على قدراتي الذاتية.
22.	لا يعانيني ما يحدث لي من مشاكل على الإطلاق لأنني أستطيع للتغلب منها بكل بساطة.
23.	أجد حلاً لكل مشكلة تواجهني.
24.	عندما أجد مشكلة جديدة ، أعرف كيف أتعامل معها.
25.	عندما يضعني أحدهم أمام مشكلة ما، أعرف كيف أتخلص منها بسهولة لأنني أملك أفكاراً عديدة لتساخلي على حلها.

استبيان الدعم الاجتماعي

لا أبداً	لا	لا	أوافق قليلاً	أوافق	أوافق بشدة
					26. هناك شخص دائماً حولي عندما أكون في حاجة إلى مساعدة.
					27. هناك شخص دائماً حولي يمكننا أن نتبادل الأفراح والأحزان.
					28. الأسرة تحاول دائماً مساعدتي.
					29. يمكنني الحصول على المساعدة والدعم العاطفي الذي أحتاجه من عائلتي.
					30. هناك شخص دائماً حولي "هو المصدر الحقيقي للراحة لي".
					31. أصدقائي حقاً يحاولون مساعدتي.
					32. يمكنني الاعتماد على أصدقائي عندما تسوء الأمور.
					33. يمكنني فعلاً الحديث عن مشاكلي مع أسرتي.
					34. لدي أصدقاء يمكنني مشاركة و تبادل الأفراح والأحزان.
					35. هناك شخص في حياتي يهتم مشاعري.
					36. الأسرة هي على استعداد دائماً لمساعدتي في اتخاذ القرارات.
					37. يمكنني التحدث عن مشاكلي مع أصدقائي.

بهذا نشهد ان الترجمة تنقل
المعنى كاملاً وصحيحاً

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يرجى قراءة كل بلد ووضع دائرة حول الرقم الذي يقدم الأفضل وصف عن مدى رضاك أنت في هذا الوقت. الرجاء الإجابة على كل بلد حتى لو كنت لا تشترك حالياً في أي نشاط أو علاقة. يمكن أن تكون راضياً أو غير راض عن عدم القيام بنشاط أو وجود هذه العلاقة.

[illegible]

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Appendix Q: Certified Translation Letter for the Qualitative Data


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ترخيص رقم ٥٥٢


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بهذا أيسر بذلك الخطوط الذهبية للترجمة
 بأن الترجمة المرفقة تنقل
 المعنى كاملاً وصحيحاً
 عنه وفصل.

Mr. Abdullah I. Al-Malki
 License No. : 552

الدكتور عبد الله بن سعود المالكي
 ترخيص رقم ٥٥٢





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 E-mail: AM6477@hotmail.com - www.linetranslation.com

Golden Lines Translation Office

To Whom It May Concern

I am the undersigned,

Mr. Abdullah Al-Malki,

Professional Arabic < - > English Translator

Golden Lines Translation Office

License No. 552


Certify that

I have translated from Arabic into English, documents related to the results' analysis of the qualitative study, and advice in writing style of the interviews' results of Mrs. Nouran Essam Katooa's Doctorate Research at RMIT University, Melbourne, Australia.

If you have any queries, please do not hesitate to contact me.

Kind regards,

Mr. Abdullah Al-Malki



GOLDEN LINES
Translation office

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